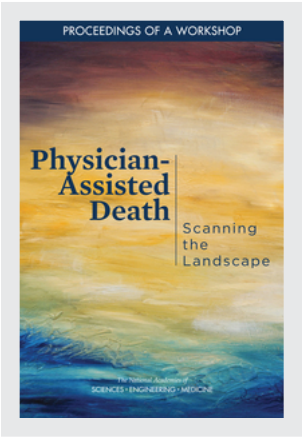


# Physician-Assisted Death: Scanning the Landscape: Proceedings of a Workshop



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# Physician-Assisted Death

## Scanning the Landscape

PROCEEDINGS OF A WORKSHOP

Rebecca A. English, Catharyn T. Liverman,
Caroline M. Cilio, and Joe Alper, *Rapporteurs*

Board on Health Sciences Policy

Health and Medicine Division

*The National Academies of*
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## PLANNING COMMITTEE FOR A WORKSHOP ON PHYSICIAN-ASSISTED DEATH: SCANNING THE LANDSCAPE AND POTENTIAL APPROACHES[1]

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[1] The National Academies of Sciences, Engineering, and Medicine's planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published Proceedings of a Workshop rests with the rapporteurs and the institution.

# Reviewers

This Proceedings of a Workshop was reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the National Academies of Sciences, Engineering, and Medicine in making each published proceedings as sound as possible and to ensure that it meets the institutional standards for quality, objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this proceedings:

**ALEXANDER M. CAPRON,** University of Southern California
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**MATTHEW K. WYNIA,** University of Colorado Anschutz Medical Center

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the proceedings nor did they see the final draft before its release. The review of this proceedings was overseen by **HUDA AKIL,** University of Michigan, and **DONALD STEINWACHS,** Johns Hopkins University.

They were responsible for making certain that an independent examination of this proceedings was carried out in accordance with standards of the National Academies and that all review comments were carefully considered. Responsibility for the final content rests entirely with the rapporteurs and the National Academies.

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## BOXES



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# Acronyms and Abbreviations

| | |
|---|---|
| ALS | amyotrophic lateral sclerosis |
| DSM | *Diagnostic and Statistical Manual of Mental Disorders* |
| EOLOA | California's End of Life Option Act |
| MRI | magnetic resonance imaging |
| ODDA | Oregon Death with Dignity Act |
| OECD | Organisation for Economic Co-operation and Development |
| POLST | Physician Orders for Life-Sustaining Treatment |

# 1

# Introduction[1]

The question of whether and under what circumstances terminally ill patients should be able to access life-ending medications with the aid of a physician is receiving increasing attention as a matter of public opinion and of public policy. Ethicists, clinicians, patients, and their families debate whether physician-assisted death ought to be a legal option for patients. While public opinion is divided and public policy debates include moral, ethical, and policy considerations, a demand for physician-assisted death persists among some patients, and the inconsistent legal terrain leaves a number of questions and challenges for health care providers to navigate when presented with patients considering or requesting physician-assisted death.

Eight U.S. jurisdictions have authorized physician-assisted death through legislation, ballot initiative, or state Supreme Court decisions—

[1] The planning committee's role was limited to planning the workshop, and the Proceedings of a Workshop was prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

**BOX 1-1**
**Statement of Task**

The Board on Health Sciences Policy of the National Academies of Sciences, Engineering, and Medicine will convene an ad hoc committee to plan a workshop that will explore current practices and challenges associated with physician-assisted death and highlight potential approaches for addressing those challenges. The workshop will provide opportunities to discuss the following issues:

- What is known empirically about the access to and practice of physician-assisted death in the United States and in other countries?
  - In states where it is legal:
    - What is known about who accesses it and the impact the practice has on the patient and family experience of death?
    - What is known about whether legal safeguards are observed?
    - What is known about whether concerns about vulnerable populations have been realized when it is practiced?
  - In states where it is not legal:
    - What is known about the current practice of physician-assisted death and what patients are accessing it?
    - Is its practice accompanied by safeguards, if any, and how do such safeguards compare with safeguards enacted in states where it is legalized?
  - What are the gaps in empirical data about the practice of physician-assisted death in the United States?
    - How do the data collected in the United States compare with the data collected in countries like the Netherlands, which have more extensive reporting and data collection?
- Explore potential approaches for physicians:
  - Who practice in a state where it is legal but are personally opposed to physician-assisted death?
  - Who receive a request for access but the situation does not adhere to the applicable state's legal framework?
  - Who receive a request for access when the practice is legal in nearby states but not in the state of practice?
- What is known about how palliative care and hospice services have incorporated the practice of physician-assisted death in states where it is legal?

The planning committee will develop the agenda for the workshop, select and invite speakers and discussants, and moderate or identify moderators for the discussions. A workshop proceedings will be prepared by a designated rapporteur based on the information gathered and discussions held during the workshop in accordance with institutional policies and procedures.

Oregon, Washington, Montana,[2] Vermont, California, Colorado,[3] Washington, DC,[4] and Hawaii[5] (Emanuel et al., 2016).

To discuss what is known and not known empirically about the practice of physician-assisted death, the Board on Health Sciences Policy of the National Academies of Sciences, Engineering, and Medicine (the National Academies) convened a 2-day workshop in Washington, DC, on February 12–13, 2018 (see Box 1-1 for the Statement of Task). The workshop was sponsored by The Greenwall Foundation.

In his introductory remarks to the workshop, James Childress, an emeritus professor of ethics at the University of Virginia, stated that the primary purpose of the workshop was not to debate the ethical pros and cons of physician-assisted death, but to understand the current landscape and identify areas where more data and research would be helpful to fill knowledge gaps. He noted that the workshop speakers and audience members represented a variety of disciplines and experiences and held diverse views about physician-assisted death, ranging from supportive to skeptical to opposed, with many gray areas and nuance in between. "Even though there are understandably divergent viewpoints," he said, "we have a shared focus on seeking to understand the practice of physician-assisted death in the United States." The intended focus of the workshop was to better understand physician-assisted death in the United States from an empirical perspective, including drawing upon experiences in the Netherlands and Canada (see Chapter 4 for international experiences).

## WORKSHOP FOCUS AND CONTENT

As stated above, the focus of the workshop was what is known and not known empirically about the practice of physician-assisted death. Throughout the development of the workshop agenda the planning committee kept in mind a number of questions derived from the Statement of Task; for instance: What are the current practices and challenges associated with physician-assisted death in U.S. states where it is legal and not legal? Who is accessing physician-assisted death and how are legal safeguards being observed? How is the practice of physician-assisted death impacting the patient and family experience of death? How are clinicians and health care institutions responding to the legalization of physician-

[2] A 2009 Montana Supreme Court decision ruled that state law protects Montana physicians from prosecution for helping terminally ill patients die. See *Baxter v. Montana*, 224 P.3d 1211 (2009). This information was added after the prepublication release.

[3] Colorado End-of-Life Options Act, Colorado Revised Statutes. 25-48 (November 8, 2016).

[4] Death with Dignity Act of 2016, District of Columbia Official Code, Chapter 6B: Physician Assisted Death, § 7-661 (November 2016).

[5] Our Care, Our Choice Act, H.B. 2739, 29th Legislature, State of Hawaii (April 2018).

assisted death? What are the gaps in empirical data about physician-assisted death and how could the collection of data to fill those gaps also inform ethical arguments surrounding physician-assisted death? The planning committee designed an agenda and invited speakers who could discuss the potential answers to some of these questions based on their expertise or personal experience with physician-assisted death.

Invited speakers were instructed to focus on the evidence and avoid lengthy discussions of the moral or ethical arguments for or against physician-assisted death. However, an unavoidable connection and a tension exist between the empirical study of the practice of physician-assisted death and the moral or ethical issues surrounding the practice. The workshop discussions were not immune to this tension. Therefore, as a factual summary of the presentations and discussions at the workshop, this proceedings contains the dialogue that took place at the workshop which includes aspects of both the empirical study of physician-assisted death and some of the associated moral and ethical considerations regarding the practice.

## TERMINOLOGY

This publication summarizes the workshop's presentations and discussions. To provide context for the workshop, Childress explained that there are broad and narrow interpretations of physician-assisted death in contemporary discourse. The narrow interpretation, he said, is embodied in laws that have legalized physician-assisted death in several U.S. states. In this context, physician-assisted death—also referred to as physician-aided death, physician aid-in-dying, or physician-assisted suicide—refers to a physician providing a patient who requests aid-in-dying a prescription that the patient can self-administer to end his or her life. Physician-assisted death in this narrow sense is distinct from broader interpretations that include physician-administered death, sometimes called active euthanasia, which is not legal anywhere in the United States (see Chapter 4 for information from the Netherlands and Canada where euthanasia and medical aid-in-dying including physician administration of lethal medication, respectively, are more broadly applied).

As described throughout this proceedings, universally agreed-upon terminology does not exist in this area. The rapporteurs have used the term "physician-assisted death" throughout, except when individual speakers used an alternative term, in which case the speaker-preferred term is used. In their presentations some speakers preferred the term "physician-assisted death" or "physician aid-in-dying," whereas others used "physician-assisted suicide." In Canada, "medical aid-in-dying" is the preferred terminology, and this encompasses physician-assisted death

as well as euthanasia (e.g., when a physician administers lethal medication at the explicit request of the patient) (Li et al., 2017).

Also as described later in this proceedings, physician-assisted death could encompass a broader interpretation that includes a number of activities such as withholding or withdrawing life-extending treatment, terminal sedation, or not attempting to feed a patient who has lost interest in eating. Again, the focus of the workshop and the term used throughout this proceedings, in the absence of a speaker-preferred term, is physician-assisted death as applied in some U.S. state laws to mean a physician providing a prescription for a lethal dose of medication to a patient in response to his or her request for the patient to self-administer.

## ORGANIZATION OF THE PROCEEDINGS

This Proceedings of a Workshop was prepared by the rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual workshop participants and should not imply consensus.

The workshop was webcast live, and online participants were able to contribute to the discussions through the hashtag #PhysicianAssisted Death. The slide presentations and videos are archived on the National Academies website.[6]

The proceedings is organized as follows:

- Chapter 2 discusses conceptual, legal, and ethical considerations in physician-assisted death.
- The next two chapters discuss experiences with physician-assisted death in the United States (Chapter 3) and in other countries (Chapter 4).
- Chapter 5 discusses legal safeguards in the practice of physician-assisted death and, in general, how some health care organizations and individual clinicians have responded to legalization.
- Chapter 6 discusses physician-assisted death in the context of other support systems for patients.
- Chapter 7 concludes the proceedings with a discussion of the evidentiary gaps.

[6] For more information, see http://nationalacademies.org/hmd/Activities/HealthServices/PADworkshop/2018-FEB-12.aspx (accessed May 19, 2018).

## REFERENCES

Emanuel, E. J., B. D. Onwuteaka-Philipsen, J. W. Urwin, and J. Cohen. 2016. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA* 316(1):79–90.

Li, M., S. Watt, M. Escaf, M. Gardam, A. Heesters, G. O'Leary, and G. Rodin. 2017. Medical assistance in dying—Implementing a hospital-based program in Canada. *New England Journal of Medicine* 376(21):2082–2088.

# 2

# Conceptual, Legal, and Ethical Considerations in Physician-Assisted Death

**Key Messages Presented by Individual Speakers/Participants**

- The 6-month prognosis for the terminal illness requirement in physician-assisted death laws is imprecise and does not clearly distinguish who is meant to be included and excluded from accessing an assisted death. (Lynn)
- Because of the unique nature of physician aid-in-dying, a unique set of tools for assessing capacity and competence—different from those used for other medical decisions focused on prolonging health—might be needed. (Strouse)
- Because physician-assisted death laws function primarily as protections for physicians, no country or state has a monitoring system capable of assessing whether or not undesirable expansions of the practice are occurring. (Kim)
- Impaired decision making is common at the end of life. There is little direct systematic data on how to assess decision-making capacity in the context of physician-assisted death. (Kim)
- The differences in the laws regarding the withdrawal of treatment and physician-assisted death reflect an attempt to translate the moral desire to allow relief from suffering into legal rules that avoid problematic value judgments—in other words, the legal rules are designed to operationalize underlying moral values. (Orentlicher)

- Neither the Oregon nor the Dutch legal model for physician-assisted suicide ensures effective control, and each is vulnerable to logical extension. (Keown)
- Few people in the United States are taking advantage of physician-assisted death laws and an argument could be made that this is not a public health crisis and the topic distracts from improving health care for the nation's aging population. (Sulmasy)
- Empirical research on this matter needs to be evaluated carefully in light of a number of potential biases and implicit assumptions, including the name ("physician-assisted death" versus "physician-assisted suicide") and the fact that a health services research approach already begs the ethical question, assuming that it is a "good." (Sulmasy)
- The question of whether this practice is "good," such that its delivery needs to be optimized, is an ethical question that cannot, in principle, be answered by empirical research methods. (Sulmasy)
- The history of repression and suffering that those with disabilities have experienced from programs of institutionalization and eugenics-driven euthanasia, all driven by health care professionals, recommends vigilance regarding physician-assisted death. However, raising administrative barriers that must be hurdled by individuals seeking equitable access to medical services just because they are identified as having a disability is mainly about health care institutions protecting themselves from criticism. Such exclusion is an improper response to ableism. (Silvers)
- Assisted suicide promotes the belief that people would rather be dead than disabled. No safeguards enacted or proposed to date will be able to stop some people's lives from ending without their consent through mistakes, coercion, or abuse. (Kelly)
- Usage of the provisions of medical-aid-in-dying laws is low, which raises the question of whether that results from an access issue or because people are not interested in accessing this option. (Callinan)
- The public does not necessarily want to take advantage of these laws, but they still want the option passed. They want control and autonomy at the end of life and the peace of mind that comes with knowing the laws are available. (Callinan)
- Any further studies of medical aid-in-dying should also include other end-of-life practices—palliative sedation, voluntarily stopping eating and drinking, and hospice. Isolating

the practice of medical aid-in-dying in research is stigmatizing and could result in incomplete data. The impact of additional research should also be weighed against patients' ability to access the practice. (Callinan)
- Data from Oregon suggest that individuals who pursue physician-assisted death primarily do so because of existential reasons (e.g., loss of autonomy, inability to participate in activities that make life enjoyable, and loss of dignity)—as opposed to alleviating pain, as is often suggested by proponents of the practice. (Callahan)
- Quality of life is a deeply personal topic that should be discussed between the patient and doctor, yet rarely is. The subject of death and dying is also a topic about which physicians need to be better educated. (Silva)

NOTE: These points were made by the individual speakers/participants identified above. They are not intended to reflect a consensus among workshop participants. The statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

## CONCEPTS AND TERMS IN PHYSICIAN-ASSISTED DEATH

While laws differ slightly across states, all require that patients requesting physician-assisted death satisfy three criteria: (1) terminal illness through a prognosis of having 6 months or less to live, (2) competence and intact judgment, and (3) voluntariness. Speakers and participants highlighted the challenges to and opportunities for improving how these criteria are defined and operationalized in the clinical setting.

### Terminal Illness and the 6-Month Prognosis

*Joanne Lynn*
*Director, Center for Elder Care and Advanced Illness*
*Altarum Institute*

Laws on physician-assisted death, as well as access to hospice, require a patient to be terminally ill, as defined by having 6 months or less to live. Joanne Lynn, director of the Altarum Institute's Center for Elder Care and Advanced Illness, explained that the 6-month criterion is not based on empirical evidence and arose in a relatively haphazard manner when the U.S. Congress was establishing eligibility for hospice services. The ambi-

guity of the 6-month criterion means it is difficult to apply clinically—it could mean that a person is nearly certain to die within 6 months, is very likely to die, or that 51 percent of people with a similar condition will be dead within 6 months.

Even with a terminal diagnosis for a single, dominant illness (e.g., cancer), death rarely follows a highly predictable course on a set time line, said Lynn. Three-quarters of Americans will die from a long-term, serious debilitating illness that can take 2 to 5 years to result in death, Lynn noted. Lynn further explained that the lead time for knowing someone has 6 months or less to live is usually a few weeks to a month for a person with cancer when his or her health worsens precipitously, or the lead time could be a matter of a few weeks or as little as a few hours for someone with a long-term debilitating illness who dwindles over the course of 1 to 2 years. Lynn stressed that it is unclear who is meant to be included or excluded through the application of the 6-month prognosis criterion for access to physician-assisted death. For individuals with a dwindling course of death due to a potential constellation of illnesses (e.g., dementia, Parkinson's disease, frailty, strokes, amyotrophic lateral sclerosis [ALS], or organ system failures), it is more difficult to predict when death will occur and, therefore, if and when these patients could gain eligibility for hospice care or physician-assisted death, said Lynn. Eligibility for physician-assisted death for a large proportion of the population will vary remarkably based on how the 6-month prognosis is operationalized (e.g., nearly certain to die within 6 months, very likely to die within 6 months, or more likely than not to die within 6 months), explained Lynn. Without predictive models, which Lynn said no organization is funding the development of, declaring a prognosis of 6 months will continue to be based on intuition rather than science. Lynn challenged the participants to consider what is really meant by the 6-month prognosis and why we, as a society, are unwilling to make this criterion more precise.

### Competency, Decision-Making Capacity, and Voluntariness

*Scott Kim*
*Senior Investigator, Department of Bioethics*
*National Institutes of Health*

Scott Kim, a senior investigator in the Department of Bioethics at the National Institutes of Health, began his presentation by agreeing with other speakers (see Daniel Sulmasy's presentation later in this chapter), that there is difficulty in achieving true objectivity and balance in considering physician-assisted death, even for an organization such as the National Academies of Sciences, Engineering, and Medicine.

Regarding competency, or the capacity of an individual to make decisions on her or his own behalf, Kim said that "decision-making capacity" is a term used in most health care laws and also in laws on physician-assisted death. Assessments of decision-making capacity are based on a set of functional criteria—for example, understanding, reasoning, appreciation—that is reflected in most states' laws (Grisso and Applebaum, 1998; Kim, 2010). Every adult is presumed to be competent unless there is a good reason to justify an assessment, such as knowing that a person has advanced dementia. Assessing competency, whether by a clinician or a judge, must account for the context of the decision and the seriousness of the decision's consequences, Kim added. He noted that there are few systematic data on how to assess decision-making capacity in the context of physician-assisted death.

One challenge in determining competency is that clinical reality does not always correspond with the clear legal constructs, said Kim. For example, some laws provide a nearly tautological or empty definition of incapacity as lacking the ability to make and communicate health care decisions, or as Kim put it, "incapacity means you are incapable, which does not guide doctors and judges all that much." Yet, a survey of psychiatrists in Oregon found that only 6 percent felt very confident that in a single evaluation they could adequately assess whether a psychiatric disorder was impairing the judgment of a patient requesting physician-assisted suicide (Ganzini et al., 1996). The same investigators found that psychiatrists' own ethical views of physician-assisted death may influence the level of scrutiny used in their assessments (Ganzini et al., 2000), and Kim and his colleagues found that two-thirds of consulting psychiatrists found decision-making evaluations to be more challenging than other types of evaluations they perform (Seyfried et al., 2013).

Kim and others have found that impaired decision-making capacity is, in fact, common at the end of life (Silveira et al., 2010). One study found that nearly half of older, terminally ill cancer patients failed a measure of capacity, with the investigators stating that "without thorough and reliable evaluation methods, doctors may fail to recognize decision-making impairments even when the impairments are pronounced" (Sorger et al., 2007). Other studies have shown that cognitive impairment is relatively common in patients with ALS, with the authors of one recent paper finding 40 percent of ALS patients in the study to have cognitive impairment (Rabkin et al., 2016).

In perhaps the most thorough study of hospice patients (both inpatients and outpatients) with no documented or clinically obvious impairments or cognitive disorders, the researchers found that 54 percent of these individuals had a significant cognitive impairment (Burton et al., 2012), said Kim. Moreover, these individuals did significantly worse than

other study participants on the decision-making capacity measure used in the study. A small study in the Netherlands found that 23 percent (5 of 22) of the people who requested physician-assisted death had psychiatric symptoms which decreased their competence in decision making. Of those who were in fact not competent, two out of five had been judged to be competent by their primary physicians (Bannink et al., 2000).

The reliability of assessments of decision-making capacity can be questionable as well, Kim said. Reliability can be high when all of the people conducting the evaluations share the same training background (e.g., psychiatry) and risk–benefit frameworks (Cairns et al., 2005), but reliability falls when the evaluators have different training backgrounds (Armontrout et al., 2016). Reliability is also low for patients in the middle of a distribution of the degree of impairment (Kim et al., 2011) compared with evaluation of patients in the tails of the distribution (Etchells et al., 1999). Reliability is also low in unsettled or novel areas of decisional capacity assessment, such as in research consent or in the context of physician-assisted death. Kim said that there are disagreements among physicians in the Netherlands in assessing the decision-making capacity of psychiatric patients requesting physician-assisted death (Doernberg et al., 2016; Kim et al., 2016). He noted that contrary to expectation, the level of scrutiny and the threshold for declaring incapacity in non-terminally ill psychiatric patients requesting physician-assisted death in the Netherlands is surprisingly low.

According to Kim, it is unknown how strong a presumption of capacity is currently being used in the United States or what thresholds are being applied in assessments of decision-making capacity for physician-assisted death. Are evaluators using a checklist to determine if a patient makes certain statements, or is there an in-depth clinical interview probing the person's understanding? Is a stand-alone community physician conducting the assessment on his or her own with little peer oversight, or is the assessment part of a larger institution's more systematic procedures with greater accountability and transparency? Also, there is a natural flow of referrals to low-threshold evaluators (people who tend to say yes rather than no)—is that desirable or undesirable, and how often does it happen? Kim suggested that all of these issues could benefit from additional research. Kim's conclusion was that a decision-making competency assessment would require more than just a conversation.

*Thomas Strouse*
*Maddie Katz Professor of Palliative Care Research and Education*
*University of California, Los Angeles*

In California, an individual wishing to take advantage of the new law must be referred to a "mental health specialist" if he or she shows

any signs of a "mental disorder." The California law does not define mental disorder other than allude to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), said Thomas Strouse, the Maddie Katz Professor of Palliative Care Research and Education and medical director at the University of California, Los Angeles (UCLA), Resnick Neuropsychiatric Hospital and the UCLA Health System Palliative Medicine Service. The current version of the DSM defines mental disorder as "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental process underlying mental functioning" (American Psychiatric Association, 2014, p. 20).

California law defines a mental health specialist as either a psychiatrist or licensed psychologist. In Strouse's view, the mental health specialist has two tasks under the law: to review the referring physicians' determination of whether the patient has the capacity to make a medical decision, act voluntarily, and make an informed decision; and to discern whether the patient is suffering from impaired judgment and whether that impaired judgment results from a mental disorder. "To do that, you have to first decide whether a mental disorder is present, then evaluate for impaired judgment, and then try to causally link those two things," Strouse said. "Again, no recipe, no guidelines, no standards that I know of to assist us in doing that." As examples of what he thinks might qualify as impaired judgment caused by a mental disorder, Strouse created four fictional cases:

- A severely depressed patient who has delusions of deserving punishment or death.
- A patient with advanced dementia who cannot recognize the impact of his or her behavior on others.
- A chronically hypomanic patient with recent impulsivity and an inability to appreciate the consequences of most actions.
- A polysubstance-dependent patient who has been impaired enough in recent years by addictions so as to have been unable to make other important life decisions.

Strouse said that his general sense is that mental health referrals related to the California End of Life Option Act (EOLOA) are made out of an abundance of caution and that there has been a learning curve with regard to referrals. There were more referrals early in the first year after California's law went into effect than there have been in the past 6 to 8 months. Often, the patients he has seen were referred because they had a history of mental disorder or were taking a maintenance dose of an antidepressant. In most cases, these individuals did not have demonstrable

active or symptomatic mental disorders when he or his colleagues evaluated them, and impaired judgment caused by a mental disorder has not been a disqualifier for these patients.

California law does provide a definition of an informed decision as it pertains to physician aid-in-dying, Strouse said, but voluntariness is an area that needs research in order for the concept to be better defined as it pertains to physician-assisted death. Most people would agree, he said, that voluntariness requires two conditions: intentionality and freedom from controlling influences. Coercion, he explained, is generally construed to mean undue influence by another person or entity. Some scholars, though, propose that the illness itself is coercive (Garrison, 2007). Strouse suggested that there might be an important difference between voluntariness to consent to a proposed procedure, such as an emergency appendectomy, and voluntariness to request a desired procedure (Nelson et al., 2011).

While there is reason to be concerned that a single 1- or 2-hour evaluation might not meet a comfortable standard for assessing capacity, Strouse said he is reassured by the fact that these patients have been followed closely by a large network of caring, attentive people who have done extensive individual and family psychosocial assessments long before they are referred to him. "In many settings, and certainly in ours, it is a much richer fabric from which we draw information that leads to decisions," he said.

Regarding capacity versus competence, Strouse said that health professionals would generally assert that they are conducting clinical evaluations of capacity, with competency being the term used when the courts become involved, particularly to assign a proxy decision maker where lack of competency is adjudicated. So far, he said, California's courts have not yet become involved in capacity evaluations for end-of-life decisions, but he expects that might happen eventually.

The components of a capacity assessment, he said, include an assessment of functional abilities, an assessment for the presence or absence of psychopathology, an evaluation of the complexity of the task demand at hand, and an assessment of the understanding of the consequences of the decision. Reassessments are also conducted in order to confirm original evaluations. When it comes to assessing the abilities needed for capable decision making, mental health professionals rely on a substantial body of research that has identified four essential components: (1) understanding treatment information, (2) appreciating the significance of that treatment information for one's own situation, (3) displaying the ability to reason with relevant information, and (4) demonstrating a logical weighing of options and expressing or communicating a durable choice (Berg et al., 1996; Eckstein and Kim, 2017). Several instruments exist to perform capacity assessments, and the relative performance of these instruments

has been evaluated (Sessums et al., 2011). However, Strouse said, these tools were organized or conceived around affirmatively offered proposed treatments, and a patient-initiated request for physician aid-in-dying is a different circumstance.

In Strouse's opinion, there are several reasons why physician aid-in-dying might need to abide by different standards for evaluating capacity than are applied to other medical decisions. In physician aid-in-dying, the patient's goal is death, while with other medical decisions the patient's goal is health. By law, patients must initiate the discussion about physician aid-in-dying, while the clinician usually initiates the discussion about most other medical procedures. In addition, for physician aid-in-dying, the law specifically outlines the process for determining a patient's capacity, mandates reporting and sign-off by a consulting physician, and requires a consulting mental health professional in the case of a mental disorder—none of which are required for other medical procedures.

In response to a question from a workshop participant about whether he believes that the number of referrals for mental health evaluations in California has been too low, Strouse said that the referral rate is currently about 5 to 6 percent, approximately the same as in Oregon. Given that the prevalence of mental disorders in an older population is approximately 20 to 25 percent, he acknowledged that the referral rate might be too low and suggested that additional research is needed to understand the decisions that physicians are making in terms of patients' mental health and competence. Pointing to another evidentiary gap, David Orentlicher, the Cobeaga Law Firm Professor and co-director of the Health Law Program at the University of Nevada, Las Vegas, added that the same type of research should be conducted on withdrawal of treatment, given that there may be the same issues regarding competence and potential coercion.

## LEGAL FRAMEWORKS

### Comparative Analysis of Legal Rules: Withdrawal of Treatment Versus Physician-Assisted Death

*David Orentlicher*
*Cobeaga Law Firm Professor*
*University of Nevada, Las Vegas*

Eight U.S. jurisdictions (California, Colorado, Hawaii, Montana,[1] Oregon, Washington, Washington, DC, and Vermont), as well as Swit-

[1] A 2009 Montana Supreme Court decision ruled that state law protects Montana physicians from prosecution for helping terminally ill patients die. See *Baxter v. Montana*, 224 P.3d 1211 (2009). This information was added after prepublication release.

zerland, have authorized physician-assisted death, in which a physician prescribes a lethal dose of medication that the patient self-administers, said David Orentlicher, the Cobeaga Law Firm Professor and co-director of the Health Law Program at the University of Nevada, Las Vegas. Belgium, Canada, Luxembourg, and the Netherlands also allow this practice, he said, as well as allowing physicians to administer the lethal dose of medication, a practice also known as euthanasia. Every U.S. state, as well as many if not most countries, allows the withdrawal of treatment, such as discontinuing ventilator-assisted breathing, dialysis, or other health care necessary to sustain a patient's life.

Orentlicher explained that there are two types of legal rules regarding end-of-life practices: Who is eligible for the death-hastening practice? And what process is required to qualify for the death-hastening practice? At first glance, he said, it seems that the law views the withdrawal of treatment very differently than physician aid-in-dying. Closer examination, though, reveals that there are more similarities than differences between these two practices.

Regarding who is eligible for these practices, there is little restriction when it comes to the withdrawal of treatment. A competent patient has an open-ended right to refuse any treatment regardless of the patient's prognosis or type of care. Withdrawal of treatment is generally permitted for incompetent patients, but living will laws may require a "terminal condition"[2] and no pregnancy. By comparison, Orentlicher said, there are significant limits for who is eligible for physician-assisted death, including decision-making capacity, the ability of the patient to perform the life-shortening act, a life expectancy of 6 months or less, and the requirement that the patient be a resident of the state where the practice is legal.

The process of qualifying for life-ending actions also differs between the two practices. For the withdrawal of treatment in the case of a competent patient, some courts require confirmation by two independent physicians of the patient's prognosis and that the patient has decision-making capacity. For incompetent patients, Orentlicher said, every state allows withdrawal of treatment when clear and convincing evidence exists, such as from a living will or the patient's discussions with family members, that the patient would have wanted treatment to be withdrawn under the circumstances. When clear and convincing evidence is absent, the law in some states allows the family to decide, while other states vary their rules

[2] "Terminal condition" for purposes of withdrawal of treatment for incompetent patients is a rather broad definition that requires an incurable and irreversible condition that will result in death in a short period of time, with or without the administration of life-sustaining treatment. For instance, a patient with insulin-dependent diabetes would die within a short period of time without insulin.

depending on the patient's prognosis, which, Orentlicher commented, starts to look more like aid-in-dying. For example, when a patient has a terminal illness, laws generally allow families to authorize the withdrawal of treatment. However, when the patient is not terminally ill (e.g., neurologic injury), the states are more likely to err on the side of life and require treatment to continue. In contrast, physician-assisted death requires an independent physician to confirm the diagnosis, prognosis, capacity, and genuine consent and may also require a psychological examination. The laws in every aid-in-dying state also require multiple disclosures to the patient, as well as three requests, two oral and one written, by the patient over a 15-day period.

Why the difference in rules between the withdrawal of treatment and physician-assisted death? "Is it because there are meaningful moral differences between 'passive' and 'active' practices that hasten death," Orentlicher asked, "or do the different sets of rules reflect concerns about how to 'operationalize' the relevant moral principles?" In his opinion, he said, the differences are about operationalizing more than about meaningful differences between the two practices. "I think what drives end-of-life law is the desire to allow relief of suffering from serious and irreversible disease," he said, an opinion that he said was based on reading the normative arguments in court decisions, articles in the medical and legal literature, and statements by religious organizations about why it is okay to refuse life-sustaining treatment. In Orentlicher's view, end-of-life law is designed so that patients can choose a quicker death when they are suffering greatly from serious and irreversible illness.

Orentlicher noted that one approach to turning that moral principle into law, which Belgium and the Netherlands have taken, is to simply have the law follow the moral principle—if a patient is suffering greatly from serious and irreversible illness, the patient would be allowed to die. What would matter is *why* the individual wants to die (e.g., unbearable suffering), not *how* the death happens (e.g., withholding therapy, taking a lethal dose of medication, or having a physician administer the lethal dose), said Orentlicher.

For context as to why the approach of the Netherlands and Belgium has not been adopted in the United States, Orentlicher reminded the workshop participants that in the 1960s and 1970s, people disagreed about the right to have life-sustaining treatment withdrawn. In the Quinlan case, the court ruled in 1976 that treatment could be withdrawn when a person had a "dim prognosis." This became the key moral principle—that the patient be suffering from serious and irreversible disease. To Orentlicher, the right to refuse treatment in 1976 looked much like the right to physician-assisted death today. Physician-assisted death currently is permitted only for terminally ill patients; withdrawal of treatment in

1976 was permitted only for patients with a serious and irreversible illness. Treatment withdrawal law followed directly from this moral principle, explained Orentlicher.

The problem with that way of operationalizing the moral principle of allowing relief of suffering from serious and irreversible disease, said Orentlicher, is that the government is in the position of deciding who must live and who may die based on judgments about the patient's quality of life, which is not the kind of power government should exercise. As a result, the courts abandoned the Quinlan standard of a "dim prognosis," and the law now allows any patient, regardless of diagnosis or prognosis, to refuse treatment. It is up to the patient to weigh considerations about quality of life and length of life, Orentlicher said. He explained that this legal standard is acceptable in terms of the moral principle that you can hasten death when seriously and irreversibly ill because the typical withdrawal of treatment scenario involves a patient who is suffering from a serious and irreversible illness.[3] In other words, he said, the legal rule does a good job of operationalizing the underlying moral principle.

In Orentlicher's view, the law's distinction between withdrawing treatment and physician-assisted death represents an important moral difference. The distinction provides a legal proxy to sort the morally justified death from the morally unjustified death. To explain the concept of legal proxy, he offered the example of a legal proxy in the form of speed limits. In the case of driving, the goal is to have people drive safely. The law could allow drivers to drive at any speed, as long as it is a safe speed. But drivers and police officers may have different views about safe and unsafe speeds, and different police officers would also vary in their views of the appropriate speed. Thus, to avoid problems with enforcing speed limits, Orentlicher continued, a specific limit is set, while recognizing that it is not a perfect reflection of a moral principle but rather a good approximation.

Because legal proxies are approximations of a moral principle, they may need refinement over time, Orentlicher said. He further explained that people have not changed their thinking as to when it is acceptable to hasten death—society still holds that it is appropriate only when a patient is suffering from serious and irreversible illness. What has changed is the way society turns that moral principle into legal rules, he said. The legal distinction between treatment withdrawal and aid-in-dying, he explained, has provided a useful proxy to sort the morally justified death from the morally unjustified death and avoid the need for case-by-case judgments. The typical withdrawal of treatment involves a patient suffering from serious and irreversible illness, while many suicides involve people suf-

[3] Other refusals typically reflect religious belief and these refusals are not always respected.

fering from a depression that should be treated, Orentlicher said. But, there are some patients suffering from serious and irreversible illness who are not dependent on life-sustaining treatment. According to Orentlicher, death with dignity laws reflect the view that the distinction between treatment withdrawal and aid-in-dying does not do a good enough job of sorting between the morally justified and morally unjustified death. By allowing aid-in-dying only for terminally ill persons, said Orentlicher, the legal rules serve as better proxies for the principle that death-hastening actions can be chosen by people who are seriously and irreversibly ill. For Orentlicher, the requirement for terminal illness places a useful and effective legal limit on aid-in-dying, one that he believes is critically important, which is why every state with aid-in-dying laws uses the criteria. By restricting aid-in-dying to terminal illness, he said, society directly limits its access to people suffering from a serious and irreversible illness.

According to Orentlicher, the restriction to terminally ill patients is reasonable even if one believes that a right to choose aid-in-dying should rest simply on patient autonomy. The requirement of terminal illness limits the risk of "false positive" cases in which a person is seriously depressed but allowed to go forward with aid-in-dying because of the wrong conclusion that they are making a genuine expression of autonomy. Orentlicher said that he expects that more states will legalize physician-assisted death if the empirical evidence continues to be reassuring, which could also lead the Supreme Court to recognize a constitutional right to aid-in-dying.

## Legal and Regulatory Landscape

*John Keown*
*Rose Kennedy Professor, Kennedy Institute of Ethics*
*Georgetown University*

In most jurisdictions, said John Keown, the Rose Kennedy Professor in the Kennedy Institute of Ethics at Georgetown University, criminal law prohibits a doctor from intentionally administering a lethal drug to terminate a patient's life, even to end suffering (which he defined as "voluntary euthanasia" if the patient requested it and "non-voluntary euthanasia" if the patient was incapable of requesting it). It is also illegal in most jurisdictions for a physician to intentionally assist a patient to end his or her life by prescribing or providing a lethal drug, which he called "physician-assisted suicide." He regarded the phrase "physician-assisted death" as both euphemistic and ambiguous: "We are not talking about assisting dying," he said. "We are talking about either intentionally ending somebody's life or intentionally helping them to end their own life." Keown noted the ambiguity in the term "physician-assisted death": some

use it to mean euthanasia and physician-assisted suicide; others used it to mean only physician-assisted suicide; and still others used it to include withholding or withdrawing life-prolonging treatment.

Keown noted that the 1997 Supreme Court rulings in *Glucksberg*[4] and *Quill*[5] drew a legal distinction between withdrawing treatment at a patient's request and physician-assisted suicide. Chief Justice Rehnquist explained that whereas everyone was entitled to refuse unwanted treatment, no one was permitted to assist suicide and that a doctor who withheld or withdrew treatment need not *intend* to hasten death. The chief justice also cited several state interests justifying laws against physician-assisted suicide including the preservation of life; the prevention of suicide; avoiding arbitrary, unfair, or undue influence; and avoiding any future movement toward euthanasia and other abuses. The chief justice added that state interests went beyond protecting the vulnerable from coercion and extended to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and societal indifference.

Keown also noted that a number of legal scholars, including Yale Kamisar and Neil Gorsuch (now a Supreme Court Justice) have argued that it is important to keep the concepts of refusal of care and physician-assisted suicide separate (Gorsuch, 2006; Kamisar, 1958). Gorsuch, for example, has argued that the refusal of care is not logically equivalent to a right to hasten death and that to equate the two is to conflate two very different things, both morally and legally (Gorsuch, 2006).

## SLIPPERY SLOPE

*Scott Kim*
*Senior Investigator, Department of Bioethics*
*National Institutes of Health*

*John Keown*
*Rose Kennedy Professor, Kennedy Institute of Ethics*
*Georgetown University*

In his presentation, Scott Kim, a senior investigator in the Department of Bioethics at the National Institutes of Health, also discussed the concept of the slippery slope, as had been requested by the workshop organizers. He discussed two types of slippery slope: first, the expansion of physician-assisted death within an accepted category of practice

[4] *Washington v. Glucksberg*, 521 U.S. 702 (1997).
[5] *Vacco v. Quill*, 521 U.S. 793 (1997).

(e.g., "terminally ill"); second, expansion in the categories of persons who can receive physician-assisted death (e.g., children, non-terminally ill, advance requests for physician-assisted death). Kim argued that data are needed to assess these two types of expansion, and he questioned whether the jurisdictions that permit physician-assisted death collect the types of data needed to evaluate how decisions are made regarding, for example, how strong a presumption of capacity is used, how terminal illness is determined, and who serves as the second opinion on those determinations. Such data are critical, said Kim, because there is no natural feedback loop to assess how the current laws are working, given that the procedure is final and the dead cannot provide feedback the way a person who has had a wrong limb amputated can.

Kim said that because physician-assisted death laws function primarily as protections for physicians (i.e., as protected exceptions to criminal prohibitions against homicides), no country or state has a monitoring system that can assess whether the two expansions in practice are actually occurring since all jurisdictions rely on the self-reporting of those performing the procedure. He added that retrospective reviews of physician self-reports by regional euthanasia review committees in the Netherlands have not proven to provide rigorous oversight (Miller and Kim, 2017) and that the large national studies in the Netherlands and Belgium will be informative but are mostly epidemiological and do not provide insight into decision making by doctors. In the United States, he noted, it is difficult to get funding to study physician-assisted death since most clinical researchers from academic medical centers are funded by the National Institutes of Health, which is organized by, and primarily interested in, specific disease areas.

### Expansion of Practice

Kim said that the U.S. practice of physician-assisted death places the autonomy of the patient at the forefront—the physician writes a prescription, and it is the patient's responsibility to fill the prescription and use it as he or she chooses, or if he or she chooses. Although the term "physician-assisted suicide" is contested by some, the term "suicide" (taking it only in the descriptive sense of self-caused death) brings out one particular fact about the U.S. system, Kim said—that it requires that the patient exhibit a high level of self-determination. Kim suggested that the term "physician-assisted death" obscures this fact because the term can cover both euthanasia and physician-assisted suicide, which leaves the role of the patient unspecified.

In Belgium, Canada, Luxembourg, and the Netherlands, Kim said, the distinction between physician-assisted suicide and euthanasia is blurred

and the important concept is "physician-assisted death by appointment" (although it is not commonly referred to by this term). In those four countries, the distinction between a physician-assisted death that is completed by injection and that is carried out by a patient ingesting a medication is mainly symbolic since all physician-assisted death is done by appointment. Kim explained that in the Netherlands, even if a patient makes an appointment for physician-assisted death with a stated preference for ingestion, the doctor brings a drink and the necessary materials for a lethal injection in case the ingestion does not work (or does not work fast enough). Self-ingestion no longer has the strong implication regarding self-determination that it does in the United States, Kim said, because it is the doctor who is providing the procedure in either scenario. Kim further suggested that this is why some Canadian institutions have the policy of providing only euthanasia (Li et al., 2017).

### Expansion of Eligible Categories: Unbearable Suffering

The categories of those eligible for physician-assisted death have expanded, Kim said. Although virtually all discussions of physician-assisted death began as a debate over how to ease the process of dying (i.e., "how to die" rather than "whether to die"), the practice has tended to expand in terms of the categories of people who are considered as candidates, he said. This has occurred by (1) removing the terminal illness requirement and substituting unbearable suffering, (2) allowing children to be eligible (as in Belgium, Luxembourg, and the Netherlands), or (3) allowing physician-assisted death for those who are incompetent to make decisions through the mechanism of advance requests.

Focusing on the first possible expansion of categories, Kim said that expanding the availability of physician-assisted death to those who are suffering unbearably could in theory require intrusive quality-of-life judgments by physicians concerning whether a person is suffering enough. "There is something not quite right about having doctors have that kind of authority given by the state," Kim said. In the United States, this question has been avoided by limiting physician-assisted death to terminal illness; no physician-assisted death law in the United States mentions a quality-of-life judgment or suffering requirements, he said. In jurisdictions that do use the suffering requirement, the problem of a state-mandated evaluation of suffering is evaded by using a subjective definition of unbearable suffering: unbearable suffering is based solely on the patient's account, said Kim. Thus, in practice the unbearable suffering criterion has been reduced to an autonomy-based, strongly libertarian justification in which the individual's preferences rule, Kim said.

Kim also described the implications of an expansion of physician-

assisted death by using the unbearable suffering criterion rather than the terminal illness criterion in terms of "red flags becoming green flags" phenomenon. For example, when the terminal illness category is in use, mental illness, despair, and hopelessness are a "red flag" that urges caution in allowing physician-assisted death. However, if a standard of unbearable suffering is used, mental illness, despair, and hopelessness become markers of unbearable suffering and thus a "green flag," or part of the justification for physician-assisted death.

Kim cautioned that the type of physician-assisted death practiced in Oregon—with terminal illness required for access and a strong focus on patient autonomy—represents a small minority (approximately 1 in 12 by rough estimate)—of physician-assisted deaths worldwide. Kim noted that even in the United States, there are signs that the advocacy for a terminal illness-based physician-assisted death is only a strategic one in which the eventual goal is a more expansive suffering-based system.

Referring to Lynn's comments on the imprecision of the 6-month prognosis criterion, Kim defended the criterion as still being useful as a "natural backstop" for the difficult discussion of medical futility. He said that in Canada the attempt to limit physician-assisted death in the general realm of end-of-life practices by using the criterion of "reasonably foreseeable death" has led to a slippery slope. Kim described how some doctors in Canada are now openly using death within 10 years as a definition of "reasonably foreseeable death." Kim further suggested that if the standard becomes unbearable suffering, medical futility becomes tied to social and health policy priorities in terms of what we are willing to devote to the treatment of various disorders. Unlike a terminal illness about which modern medicine can do nothing to stop eventual death, whether someone finds suffering from a non-terminal illness "intolerable and irremediable" will depend greatly on the quality and quantity of medical and social programs available to that person. To permit physician-assisted death for such persons is less resource intensive and less costly than making high-quality care universal, Kim said. In addition, he said, determining whether such a person qualifies for physician-assisted death will always be an implicit judgment by society about the worth of some lives over others. Kim suggested that considering these moral questions is important for society for various reasons, not least of all is to inform the kinds of data collected on the practice of physician-assisted death.

### Practical and Logical Slippery Slopes

Keown argued that it is not feasible to have effective legal control of either voluntary euthanasia or physician-assisted suicide. He invoked two "slippery slope" arguments: the "empirical" and the "logical." The former

suggests that it is not feasible either to draft or to enforce effective safeguards; the latter holds that safeguards (such as the requirement of a voluntary request or a "terminal illness") are vulnerable to logical extension.

Keown referred to Capron's conclusion that the safeguards in Oregon's Death with Dignity Act are "largely illusory" (Capron, 1996). Capron pointed out that any doctor could act as one of the two practitioners who must approve the request; neither physician needs to have any prior knowledge of the patient or expertise in psychological evaluation, and any physician inclined to set up a practice specializing in physician-assisted suicide could become a magnet for terminally ill people from around the world. Moreover, the act does not require the second doctor to be independent of the first, so both could be partners in the same physician-assisted suicide practice. Furthermore, Keown said, the Oregon law relies on self-reporting after the fact by the physician involved, and the Oregon Health Authority has acknowledged that it cannot detect or collect data on issues of noncompliance with any accuracy. As Gorsuch observed, the Oregon law made reliable and relevant data and case descriptions difficult to obtain (Gorsuch, 2006).

Gorsuch had suggested that answers to the following questions were essential to understanding the effects of the Oregon law and necessary to provide a thoughtful assessment of the law's worthiness for emulation elsewhere, but that there was little chance that these questions would be answered anytime soon given the many limitations that the law placed on the Oregon oversight agency (Gorsuch, 2006):

- What role was depression, as opposed to terminal illness, playing in patients' decisions to die?
- Were alternative options, including treatment for depression, being fully presented, or presented at all?
- Were the doctors who prescribed death even knowledgeable about the alternatives?
- To what extent were family members unduly influencing patient choices and physician evaluations?
- Do physicians and psychologists have a duty to perform more than a cursory examination?
- Should prescribing physicians consult the patient's primary care providers and other doctors who may have declined to provide a lethal prescription?
- Do health maintenance organizations have a conflict of interest, given that assisting suicide is undeniably cheaper than continuing care?
- How many cases were not reported, and how accurate were the reports that were filed?

Keown also discussed whether the principles underlying the Oregon law made it vulnerable to extension. He cited Capron's questions, including: Why should physician-assisted suicide be available only to the "terminally ill" but not the chronically ill? Why physician-assisted suicide but not voluntary euthanasia? Did denying an injection to those unable to end their lives even with assistance not constitute unjust discrimination on the basis of disability? Keown noted that Chief Justice Rehnquist had observed in *Washington v. Glucksberg* that what might seem a limited right to physician-assisted suicide was actually a much broader license that could prove extremely difficult to police and that the expansion of this practice seemed all but inevitable.

Keown described another difficult moral and legal question that emerges if laws like Oregon's are changed to allow voluntary euthanasia. Once laws allow for voluntary euthanasia, why not extend them further to allow non-voluntary euthanasia? Why deny incompetent patients a merciful death? Keown noted that the Dutch law allowing voluntary euthanasia has not prevented non-voluntary euthanasia. He observed: "Six comprehensive national surveys in the Netherlands have disclosed that since it was declared lawful in 1984, thousands of patients have been given lethal injections without their explicit request and thousands of cases have not been reported by physicians." He added, "It is difficult to conclude, therefore, that the Dutch system, which has now twice been criticized by the UN [United Nations] Human Rights Committee, has been a model of effective control."

Keown reported that one Dutch ethics scholar, Theo Boer, who served on a euthanasia review committee from 2005 to 2014, has turned from a supporter to a critic of the Dutch law and declared that the "explosive" increase in euthanasia cases showed that "some slopes truly are slippery" (Center for Bieothics & Human Dignity, n.d.; Doughty, 2014). Moreover, in 2016 Boer observed that in approximately 45,000 cases of euthanasia and assisted suicide reported in the Netherlands since 2002, only 75 had been referred by the review committees to the public prosecutor and not a single case had resulted in prosecution.[6] Boer explained that public opinion in the Netherlands has begun to interpret "assisted dying" as a right, not an exception, and that legalization has led to a normalization and a general expansion of the practice. Boer concluded that supply creates demand and that many who would never have considered euthanasia 10 years ago now say, "Why not"?[7]

Keown also noted that in 2016 the Dutch government announced its proposal to extend the law to allow assisted suicide for older individu-

[6] Personal communication between John Keown and Theo Boer, August 16, 2016.
[7] Personal communication between John Keown and Theo Boer, August 16, 2016.

als who may be healthy but feel their life is "completed" and that Dutch courts have, logically, used the same justification they used to justify voluntary euthanasia—namely the doctor's duty to alleviate unbearable suffering—to permit non-voluntary euthanasia in the case of disabled infants (Keown, 2018).

Keown concluded that the wording, interpretation, and application of laws—and the principles underlying those laws—are at least as important to an understanding of the end-of-life landscape as statistical data, not least because whatever data are available may largely reflect changes in the laws or their interpretation.

## REFLECTIONS ON THE ETHICS OF PHYSICIAN-ASSISTED DEATH

### Empirical Research and Controversial Medical Practices

*Daniel Sulmasy*
*André Hellegers Professor, Kennedy Institute of Ethics*
*Georgetown University*

Addressing the subject of empirical research about controversial medical practices, Daniel Sulmasy, the André Hellegers Professor of Biomedical Ethics at Georgetown University's Kennedy Institute of Ethics, said it is important to be aware of both the potential contributions and the methodological limitations of "descriptive" ethics research (Sugarman and Sulmasy, 2010). For example, one must take note of how one's personal and political views affect that research and may even influence the types of hypotheses one generates. In the case of physician-assisted suicide, said Sulmasy, opponents will look for evidence of abuse, whereas proponents will look for signs of reassurance. The scientific ideal is a dispassionate, disinterested desire to know the true state of affairs, noted Sulmasy. For example, a 2017 paper from Canadian researchers presented a straightforward, formal cost–benefit analysis of medical assistance in dying in Canada (Trachtenberg and Manns, 2017). However, Sulmasy said, bringing up the linkage between cost containment and medical assistance in dying in the United States is largely off-limits, and we should be considering why that is the case.

Sulmasy questioned why the National Academies found this topic worthy of holding a workshop. Physician-assisted death is not a public health crisis, said Sulmasy, given how few people in the United States are taking advantage of these laws. Thus, Sulmasy said, an argument can be made that this topic is not critical and even distracts from more pressing issues such as improving health care for the nation's aging population.

Sulmasy cautioned that taking a "health services research" approach to physician-assisted suicide, such as in this workshop, presumes that the goal of physician-assisted suicide is "good" and that, alternatively, the "bad" becomes assessed in terms of efficacy, safety, cost, and access. This takes the central ethical question of whether the service ought to be delivered in the first place off the table, suppressing critical debate, Sulmasy said.

A potential result, intended or not, of having a workshop such as this is the normalization of physician-assisted suicide, Sulmasy said. If the subject is worthy of examination by the National Academies, he said, it becomes medicalized as a subject for empirical study. He wondered if the workshop was to be a prelude to a National Academies consensus study that would serve to promote physician-assisted death.

Language is important because it shapes attitudes and approaches to research, he said. There is no scientific basis for deciding on terminology, other than perhaps marketing science, he said, adding that he chooses to use the term "physician-assisted suicide." From his perspective as an ethicist and social sciences researcher, he said, he finds that there are important distinctions between physician-assisted suicide, euthanasia, vigorous symptom control, and forgoing life-sustaining treatment, all of which, Sulmasy said, could be included by a reasonable person under the umbrella term "assisted death." In that regard, he urged caution when using terms that are more political than ethical or scientific in the way they are constructed.

Community engagement is a new standard for research involving human participants and serves to inform the agenda and approach for research, Sulmasy said. In determining who gets to represent "the community," he said, it is desirable to avoid using advocacy groups for this purpose. Or, if advocacy groups are used, it is important to ensure a balanced representation of proponents and opponents of a particular issue. Sulmasy suggested that opening this workshop with a presentation from a leading advocate of physician-assisted suicide was not a balanced, fair representation of the issues intended to inform a serious engagement of the questions surrounding physician-assisted suicide (see Box 3-1 for the presentation by Dan Diaz, Compassion & Choices).

A study's design must also be carefully considered, Sulmasy said. He criticized proponents of physician-assisted suicide for relying on unscientific online polls that have found physicians to be in favor of legalizing physician-assisted suicide when there are other, equally unscientific, polls reaching the opposite conclusion. In fact, the only national, weighted, probability-based random sampling study—from 2008—found that 69 percent of physicians opposed legalization (Curlin et al., 2008). Sulmasy criticized as well the use of "ambiguous, complex, and leading questions" in surveys used by proponents of physician-assisted suicide.

A second issue concerning study design involves the use of the metaphor "scanning the landscape" in describing the study of this subject, said Sulmasy. A landscape appears differently to people who are differently situated. Whether you are sitting in front of a desk in a think tank or sitting in a wheelchair matters in terms of evaluating the data, he noted. Biases also exist in recruiting participants for a study, particularly when using advocacy groups to help with the recruitment process. Sulmasy also noted that cognitive dissonance can lead to biases in retrospective surveys of surviving family members.

Relying on results from legal reporting in state-sponsored databanks has various problems as well, Sulmasy said. The data are collected in a manner that maximally protects patient privacy. Given these limitations, the data are "thin," he said, and give the bureaucratic appearance of monitoring, but the reports are not well validated, and they do not capture unreported cases. The European experience, he added, has been that there are a significant number of unreported cases.

Data interpretation can also be subject to bias, the direction of which depends on whether one is an opponent or proponent of physician-assisted suicide, said Sulmasy. Abuse is inevitable for any law, Sulmasy said, but the question is, How much abuse is too much? "That is not going to be decided by the data themselves," he said. "It is going to be dependent upon people's attitudes and their ethical sensibilities." For example, studies have appeared to show that there is no slippery slope toward undesirable expansions of physician-assisted suicide because the disabled and minorities are not overrepresented among those who seek assisted suicide. However, that does not answer the question from the point of view of those who are disabled. For many of these individuals, Sulmasy said, the fact that dependence on others has become a socially sanctioned reason to be made dead is *itself* a threat to their dignity even if they are not themselves seeking assisted suicide. Regarding what the pitch of the slippery slope actually means, he said, this will not be determined by research, but rather by serious discussion from an ethical and policy perspective.

Though many are reassured by the fact that only small numbers of people are taking advantage of these laws, Sulmasy questioned why it would be bad if the numbers were large if this practice is thought to represent good care. He also noted that the year-to-year increases seen in Oregon show that, to some extent, there is an increasing social comfort in prescribing lethal medications and using them. A topic deserving of study is the psychological slippery slope, or how practitioners and patients begin to see this as part of normal practice and whether there is pressure to participate.

Sulmasy stressed the importance, particularly for people attending a workshop such as this, of realizing that scientific facts are not ethical arguments (Sugarman and Sulmasy, 2010). "We have to pay attention to what is called the naturalistic fallacy or the fact/value distinction, the fact that you cannot derive what we ought to do from a series of facts," he said. "Good policy is based on both facts and ethics." He said that one must be aware that invalid causal inferences can lead to invalid conclusions, citing as an example the inference that the legalization of physician-assisted suicide improved palliative care in Oregon because palliative care improved after Oregon legalized the practice. It is not valid to claim that palliative care improved as a result of legalized physician-assisted suicide in Oregon, Sulmasy said. Correlation is not causation, he concluded.

He argued, too, that ethical issues should be decided based on ethical arguments, not polls, and that the attitude that "the practice is legal, so just deal with it" can lead to a political effect that promotes a controversial practice. Laws that are ethically wrong can be changed, he said. Quoting Aristotle, he said, "Ethics is about what to do when what to do is up to us." He cautioned as well about drawing the conclusion that science and medicine are moving toward accepting assisted suicide based on what appears in the literature. Journal editors have a bias toward what is new. "That means defense of the status quo is not new and does not get published," he said.

Based on data collected thus far, Sulmasy contended that what is known about physician-assisted suicide in the United States is:

- The number of reported cases that follow the law is small, but increasing;
- Those who make use of the law tend to be white, wealthy, and educated and to have a "dismissive" personality style focused on control;
- A small but growing number of physicians write lethal prescriptions;
- A substantial proportion of patients seeking physician-assisted suicide are depressed;
- Very few requesting patients are sent for psychiatric referrals;
- Individuals are not requesting physician-assisted suicide because of unbearable symptoms related to their disease, but rather due to loss of autonomy, independence, and control; and
- Approximately one-third of patients who fill a lethal prescription die without taking the drugs, either because they died too soon or decided not to use the drugs. Sulmasy cautioned that, based on this observation, it cannot be assumed that these patients only wanted the security of having "a way out."

Going forward, Sulmasy said, he would like to see serious deliberative polling, not just snapshots with loaded questions. He also called for research on the validity of the legal reporting mechanisms in order to gain a better understanding of whether those data are true or not and of the incidence of abuse. Research should also look at the psychiatric effect of assisted suicide on families, given the data from Switzerland reporting posttraumatic stress disorder in families that have witnessed assisted suicide (Wagner et al., 2012), and on incomplete suicides and whether, how, and where they are completed. More data are needed on the effects of physician-assisted suicide on individuals with psychiatric disorders, given the reports that publicity about the practice triggers an increase in suicides (Marzuk et al., 1993, 1994) and studies showing increases in suicide in the general population in states that have legalized physician-assisted suicide (Boer, 2017; Jones and Paton, 2015). Concluding his comments, Sulmasy proposed a thought experiment. "If this is just normal medicine, why are we not doing randomized controlled trials to find out how well, efficiently, and cost-effectively we can implement physician-assisted suicide? If that is disturbing, then maybe it would be a good study to find out why."

## Disability and Physician-Assisted Death

*Anita Silvers*
*Professor*
*San Francisco State University*

*John Kelly*
*New England Regional Director*
*Not Dead Yet*

Anita Silvers, a professor in and the associate chair of the Philosophy Department at San Francisco State University, addressed the particular ethical concerns for individuals with severe physical disabilities. The history of repression and suffering that those with disabilities have experienced from programs of institutionalization and eugenics-driven euthanasia, all driven by health care professionals, recommends vigilance regarding physician-assisted death, Silvers said. However, raising administrative barriers that must be hurdled by individuals seeking equitable access to medical services just because they are identified as having a disability is mainly about health care institutions protecting themselves from criticism, she said, arguing that such exclusion is an improper response to ableism.

Silvers noted that for disabled individuals, the requirement that the lethal prescription be self-administered can pose a problem. The self-

administration eligibility requirement, said Silvers, who herself is a post-polio limited quadriplegic who said she doubted that she could open 100 capsules without spilling the medication, is intended to guarantee that the final act is voluntary. She pointed out, though, that being able to control the movements of one's body does not guarantee that what one's body does is voluntary, nor that such physical control is necessary, given that U.S. courts have ruled that individuals who lack manual control can use equipment to exercise their right to refuse treatment (Applebome, 1989).

Silvers noted that a model being used for California hospital policies explicitly requires that all patients with disabilities must undergo a thorough assessment for consenting ability beyond what is required by the California aid-in-dying act. She hopes that in the same spirit of protectiveness, the added cost to the disabled patient in time and money will be weighed when considering policies such as this one. "Suffering this kind of legally endorsed exclusion, having to bear such socially imposed loss of commonplace options due to disability nearly every day, that is what my life is like, and it remains one of the hardships of living with a disability," she said. The current legalization approach to self-administration eligibility is counterproductive, Silvers concluded, because it coerces terminally individuals with a progressive deterioration of bodily control into shortening their own lives prematurely in order to maintain their options.

John Kelly, the New England regional director for Not Dead Yet, an organization that has opposed assisted suicide for 20 years, said that people with terminal conditions and those with disabilities share much in common in that both need assistance from others and are both identified as terminal. At the same time, he said, while non-disabled people are often considered terminal, people with terminal illnesses are almost never described as disabled, which he said helps explain why proponents sometimes say that no disabled person has been affected by these programs. He noted, too, that two-thirds of the people who Jack Kevorkian helped die in the late 1990s were non-terminal disabled individuals even though his victims were sometimes reported in the media as being terminally ill.

Kelly said that popular culture carries the message and educates the public that disabled lives are not worth living. In one film, *Me Before You*, the main character—a disabled man—insisted on being euthanized in Switzerland because he did not want to inconvenience his girlfriend by having her accompany him to multiple hospital visits.

Kelly said that advocates of physician-assisted suicide are pushing for non-dying, severely disabled people such as himself as well as those with long-term depression to be considered eligible under the laws. He

also said that data from Oregon show that non-terminal people do receive lethal prescriptions, with one person living 603 days after being declared eligible and another person living 1,009 days. "For me, the fact that so many people who are non-terminal are getting these drugs should be reason to stop it," Kelly said. "A public health program with such an error rate would never be tolerated." In his view, he said, assisted suicide is beginning to be considered a right, which means it would no longer be a medical practice.

Kelly reported that the leading suicidal motives reported by doctors in Oregon revolve around distress about disability and the loss of autonomy through dependence on others, the loss of abilities, a loss of dignity, suicidal despair over incontinence, and the devastation of feeling like an emotional or financial burden to others. Kelly said that these reasons reflect disability and that there are many people living with such disabilities who are fine with their lives. In his view, he said, the name of the Oregon law, Death with Dignity, means dying to avoid the so-called indignity of being disabled and dependent on others. Assisted suicide, he added, promotes the belief that people would rather be dead than be disabled like he is.

The economics of assisted suicide, Kelly said, make for a deadly combination with the nation's broken, profit-driven health care system. Some have predicted that economics, and not the quest for broadened individual liberties or increased autonomy, will drive assisted suicide to become acceptable practice (Humphry and Clement, 2000). Kelly mentioned several individuals who were denied treatment because of cost but offered assisted suicide, including one woman who found her copay for assisted suicide would be $1.20. He also said that if the nation were to provide fully funded home care for everyone, people would not have to weigh their own legacy versus their care and perhaps end up choosing assisted suicide.

Provisions in the Oregon and Washington laws also create the possibility of abuse, particularly for older individuals and the disabled, Kelly said. In those states, he said, a friend, relative, or heir can encourage an older person to make the request for assisted suicide, sign the forms as a witness, pick up the prescription, and even administer the drug with or without consent because no objective witness is required at death. Another shortcoming of the laws, he said, is that neither doctors nor witnesses need to know the patients more than superficially. Witnesses can simply check the person's identification, and doctors who decline for medical reasons are not interviewed, which means that people can doctor shop until they find someone willing to prescribe the lethal medication. In Oregon, he added, the Oregon Health Authority lacks the ability to investigate violations of the law.

In 2017 only 5 of 218 (2.3 percent) receiving lethal prescriptions for physician-assisted suicide in Oregon were referred for psychological or psychiatric evaluations (Oregon Health Authority, 2018). In Massachusetts, the pending legislation that would legalize physician-assisted suicide requires a psychiatric evaluation, but, Kelly said, few psychiatrists believe they can diagnose depression in one visit. Also, Kelly said, people who have experienced depression report that it is not difficult to pass as not depressed in a one-off meeting with someone you have never met before. Thus, Kelly expressed concern that depressed people are threatened by this legislation—especially because depression is constructed as a rational response to terminal illness.

Assisted suicide laws, he concluded, are at their core immunity laws. What he means by that, he explained, is that everyone involved in the process of obtaining the lethal drugs and administering them can receive full immunity simply by saying they acted in good faith. He criticized the emphasis put on preventing suicide in young people while simultaneously steering disabled people and those disabled by their illness toward suicide. "If assisted suicide is legal, some people's lives will be ended without their consent through mistakes, coercion and abuse," Kelly concluded. "No safeguards have ever been enacted or even proposed that can prevent this outcome, which can never be undone."

## Advocating for the Option of Physician-Assisted Death

*Kim Callinan*
*Chief Executive Officer*
*Compassion & Choices*

*Omega Silva*
*Professor Emeritus*
*George Washington University*

Kim Callinan, the chief executive officer of Compassion & Choices, an organization that works to pass medical aid-in-dying laws in the United States, said that her main concern regaining medical aid-in-dying is its availability, not its usage. Currently, she said, usage of the medical aid-in-dying laws is low, which raises the question of whether that results from a lack of access or because people are not interested in accessing this option. While large numbers of people may not be taking advantage of the option, she said, they still want the option passed.

In the United States there is strong support for medical aid-in-dying laws, Callinan said. She noted that the Colorado law passed by a 30-point margin, larger than any ballot initiative in Colorado history, and it drew

support in every area of the state and among every demographic. When the Gallup polling organization asked Americans in 2015 whether doctors should be allowed by law to assist a person who has a disease that cannot be cured and is living in severe pain to commit suicide if the patient requests it, 68 percent said they should, and 28 percent said they should not (Dugan, 2015). Similarly, a 2016 survey by LifeWay, which Callinan explained is a Christian organization, found that two-thirds of Americans believe it is morally acceptable for terminally ill patients to ask their doctors for help ending their lives and that majority support was found in a variety of demographic groups (Smietana, 2016). In particular, she said, support is strong among the Latino population as well as among Latino leaders, including Dolores Huerta, Mauricio Ochman, and Jorge Ramos, who see this as a civil liberty issue (Compassion & Choices, 2017; Gonzalez-Portillo, 2017; Huerta, 2017). Three Latino organizations have endorsed medical aid-in-dying—the National Hispanic Council on Aging, Hispanic Health Network, and Latino Commission on Aid (Red Latina, 2017; Reisman, 2018). In terms of African American support, Callinan noted, aid-in-dying legislation passed in Washington, DC, a heavily African American city, and all but one African American city council person voted in favor of the law (Markoe, 2016).

Callinan suggested that physicians are increasingly recognizing that medical aid-in-dying is an option people want. Surveys of state medical societies in Colorado, Maryland, and Massachusetts found that a majority of their members supported medical aid-in-dying, which led to those three organizations dropping their opposition to these laws (Colorado Medical Society, 2016; Maryland State Medical Society, 2016; Massachusetts Medical Society, 2017). Seven more state medical societies have since followed suit (Callinan, 2017; Compassion & Choices, 2018). Callinan said that public support for these laws reflects the desire of many to have control and autonomy at the end of life. A 2016 paper recognized this desire by consumers and called on the medical profession to figure out how to bring this option to the public (Frye and Youngner, 2016). In addition, the New York State Academy of Family Physicians has decided it is a duty of medical professionals to help people with this option in a way that is safe and effective and that declining to do so was a form of patient abandonment (Fandl, 2017).

Callinan suggested that one challenge in implementing U.S. laws on medical aid-in-dying is that the determination of a 6-month prognosis often comes too late for many patients. Data show that a large majority of people are not getting a 6-month prognosis until they have 3 months to live, after which time they need to go through a lengthy process to determine their eligibility and receive a prescription for lethal medica-

tion (Brody, 2007; Christakis and Lamont, 2000). In a supportive system, it is possible to go through the process of requesting and receiving a lethal prescription in 15 days, Callinan said, but most people are not in a supportive system, and for those individuals it can take months to obtain their prescriptions. Callinan suggested that an interesting research question is to find the appropriate balance between legal safeguards and access to medical aid-in-dying.

She suggested that any further study of medical aid-in-dying should include other end-of-life options—withdrawal of treatment, palliative sedation, and hospice—because little is known about any of these options. Callinan argued that it is intrusive and stigmatizing to patients who choose medical aid-in-dying to focus only on research on medical aid-in-dying. Practices such as palliative sedation can be more dangerous than medical aid-in-dying. While there are multiple regulatory protections in place for medical aid-in-dying, Callinan said, there are no regulations on palliative sedation.

Callinan said she would also like to see research on why patient demand for medical aid-in-dying has increased in recent years and how that increase should inform the delivery of patient-directed care. She would also like data to illuminate which legal safeguards and regulatory requirements are necessary and which ones create unnecessary delays and stigma. However, she cautioned that additional data collection efforts or requirements might affect patients' ability and willingness to access medical aid-in-dying by making the request process too onerous for both doctors and patients.

Callinan suggested that another area of research could examine the impact of not passing medical aid-in-dying laws. For instance, are people committing suicide instead of having a peaceful death because medicine is not meeting their needs? Does a lack of medical aid-in-dying laws create a more dangerous underground practice? Callinan questioned whether, given the small number of people who choose to access medical aid-in-dying and the lack of evidence of any abuse or coercion taking place, research dollars are best spent on studying this or other end-of-life options.

Omega Silva, a professor emeritus of medicine at George Washington University and a patient familiar with the District of Columbia's recently passed medical aid-in-dying program, said that quality of life is a very personal topic which should be discussed between the patient and doctor. She suggested that the subject of death and dying is a topic about which physicians need to be better educated. Silva suggested that medical school curricula should include an early introduction and continuous referral to end-of-life issues.

## Values and Ethics in Conversations About Physician-Assisted Death

*Daniel Callahan*
*Co-Founder and President Emeritus*
*The Hastings Center*

Daniel Callahan, a co-founder and the president emeritus of The Hastings Center and a senior scholar at the Institute of Politics and Policy Studies at Yale University, began by reminding the workshop participants that there was a time when a person with the right connections could easily find a physician who would supply a patient with a lethal dose of medication. Physicians would even sometimes euthanize a patient without the patient's permission. In the 1980s, overt advocacy for euthanasia in the United States became more common, and there were reports, later confirmed by the Dutch government, that euthanasia without a patient's permission was occurring in the Netherlands. It was around this same time, in 1989, that Oregon passed its Death with Dignity Act.

Callahan said he came to the debate on assisted death with both wariness and curiosity. Through his work on end-of-life care and the emerging hospice movement, he was well aware that many deaths could be painful, psychologically traumatizing, and messy. But he wondered why hospice was not enough. He also became interested in the observation that medical progress was exhibiting the unpleasant feature of moving society from short lives and quick deaths to longer lives and extended dying.

The autonomy of individuals and their ability to chart their own course of life is at the core of arguments in favor of both assisted death and euthanasia, said Callahan. The argument for autonomy raises a key question, according to Callahan: How far can the liberty to die one's own chosen death go, and when ought the collective good come into play? The values underlying that question were raised in an interesting way when in the early 20th century, laws outlawing suicide were rescinded across the United States, said Callahan, which had the de facto effect of making suicide socially acceptable. Callahan said that some 43,000 Americans commit suicide annually (O'Brien, 2018). Today, suicide is judged to be a public health problem, and there are anti-suicide efforts at federal and state levels.

Suicide prevention and assisted death programs have nothing to do with one another bureaucratically in Oregon, Callahan said. There are, however, what Callahan called provocative new data emerging that the number of "ordinary" suicides increased in parallel with that of assisted suicide (Dugdale and Callahan, 2017). Callahan suggested this

is not coincidental—his hypothesis is that the Oregon assisted-death law brought considerable media attention to suicide as an acceptable way to deal with the travails of one's life. During the discussion with workshop participants, this hypothesis was contested by a workshop participant, who cited an article in the *Southern Medical Journal* (Jones and Paton, 2015) as well as his own unpublished analysis using data from the Centers for Disease Control and Prevention, which found that the increase in non-assisted suicide rates was not statistically significant.

Another argument used by proponents of assisted death is that the option is necessary to alleviate pain and suffering. But among those who want to take advantage of Oregon's law, only 25 percent cite inadequate pain control, Callahan said. Instead, existential reasons, including the loss of autonomy (89 percent), the inability to engage in activities that make life enjoyable (89 percent), and loss of dignity (77 percent), are the main reasons given by those requesting assisted death in Oregon according to physician reports of patient concerns (Oregon Health Authority, 2018). Callahan questioned whether these existential burdens mirror the troubles of many older individuals.

Callahan was baffled by the word "dignity" in the context of assisted death. Are individuals less human because they may have bouts of incontinence, momentarily forget the names of their own children, or no longer be allowed to drive? Referring to Article 1 of the United Nations Declaration of Human Rights (UN, 1948), which says that all human beings are born free and equal in dignity and human rights, Callahan said he assumes that the UN statement encompasses the end of life as well as the beginning and that it is not undone by existential burdens. "Moreover," he said, "I trust that it does not mean that indignities in any sense destroy our basic dignity."

Callahan reflected on his understanding of how assisted death in the Netherlands has expanded to undesirable uses of the practice. He suggested that the concept of personal freedom is being applied in the Netherlands to mean that individuals with mental illness and depression as well as general boredom with life are suitable for an assisted death. Despite his opposition to assisted death, Callahan said he believed the option would continue to be legalized in other U.S. states. He warned that increasing access to assisted death is a poor solution, but for many it may be the only solution available because we have not yet learned how to deal with drawn-out death—the downside of medical progress. Callahan predicted that good hospice programs would be able to minimize the harms of the spreading assisted-death movement but that harm will be inevitable. He said that his hope for the future is to increase research and discussion about assisted death and aging societies.

## DISCUSSION

During open discussion periods with workshop participants, speakers and participants addressed a number of aspects of physician-assisted death.

### Terminology

A workshop participant asked speakers to comment on whether they thought the term "facilitated natural death" was a better description than "physician-assisted death." Keown objected to this terminology and suggested that society should not pretend that physician-assisted suicide is anything other than an unnatural death. Reflecting on this question, Orentlicher said that there is no neutral terminology on this subject and suggested that individuals pick the term that conveys their beliefs or agenda.

Linda Ganzini from the Veterans Affairs Portland Health Care System suggested that whatever terminology is used, there are ways of developing research and evidence to understand how physician-assisted death is similar to or different from suicide in other contexts. This information, she added, would be useful for patient care and for identifying the appropriate intervention to help patients and families. A workshop participant noted that in October the American Association of Suicidology issued a policy statement distinguishing medical aid-in-dying from suicide (Creighton et al., 2017). Kim responded that comparing the features of what the association's statement calls "suicide in the ordinary, traditional sense" and the features of persons receiving psychiatric euthanasia show that it is in fact very difficult to differentiate between the two, contrary to the claims made in the association's statement.

Further reflecting on the term "facilitated natural death" suggested by a workshop participant, Orentlicher questioned why a natural death would be preferred over unnatural death, noting that if natural was preferred over unnatural, there would not be heart bypass surgery, chemotherapy, or the medical profession, as each of those takes us away from our "natural" state of being. Drawing on his experience in the UCLA system, Strouse added that one difference between suicide and physician-assisted death is the extraordinary impact of opening a discussion among patients and families about end-of-life options which enables them to prepare and accept their loved one's impending death.

### Workshop Agenda and the Role of Advocacy Organizations

Sulmasy raised an issue about the workshop agenda and questioned the representation on the agenda of the main U.S. advocacy group for

legalizing assisted suicide, Compassion & Choices. He asked what the proper role (if any) should be for an advocacy organization participating in a scientific meeting and whether this might indicate one of the sorts of problems he noted in his initial presentation regarding potential sources of bias in empirical research about ethically controversial health policies.

### Physician-Assisted Death and Economically Marginalized or Minority Populations

A workshop participant asked what is known about the impact of physician-assisted death on vulnerable or economically marginalized populations. Sulmasy answered that there is some evidence to suggest that lower socioeconomic status patients are less interested in physician-assisted death, but we know very little about the impact of the practice on this population. Anthony Back of the University of Washington reflected on his experience working in a safety-net hospital in Seattle and suggested that economic factors are not playing a significant role in patients' decisions to request physician-assisted death. Ganzini said that in an Oregon comparison between physician aid-in-dying deaths and all other Oregon deaths, those who received aid-in-dying were eight times more likely to have had at least a bachelor's degree. Ganzini said that she has found from her research that financial concerns are rarely a reason why people request physician aid-in-dying; only approximately 2 percent of the people she studied who received aid-in-dying lacked health insurance.

Scott Halpern of the University of Pennsylvania asked if differences in use of physician-assisted death and endorsement of the practice among different racial and ethnic groups suggests that there is a disparity in access or a difference in preferences. Callinan said that in her experience, people support this issue because they have experienced a loved one who had an unpleasant or painful death. In her opinion, she said, the issue comes down to consumer empowerment which comes with knowing that one can get the prescription medication to end one's life. Callinan suggested that the desire for autonomy and control over the end of one's life is observed across all groups, although access is an issue within African American and Latino communities. Silva said that people asking for physician-assisted death usually have a relationship with a physician, which is something that many in minority communities do not have. Daniel Callahan said that the majority of people who request assisted death in Oregon are well educated, and he wondered if assisted death is a form of boutique health care for the "1 percent" in the same way that it previously was possible for the wealthy to receive an assisted death from their physician friends. Callinan and Silva suggested that additional research could help to better understand challenges in access to physician-assisted death.

### Mental Health Referrals

A workshop participant questioned data from Oregon indicating less than 5 percent of those who received a prescription for lethal medication had also been evaluated by a mental health professional. For instance, could the 5 percent be misleading since it does not count the number of individuals who are disqualified early on from continuing in the request process for physician-assisted death because they exhibit clear mental disorders or lack of capacity? Ganzini confirmed it is true that, in Oregon, it is unknown how many people receive a psychiatric evaluation and are as a result excluded from continuing in the request process. Reflecting on her experience seeing patients, Ganzini said it often happened that a patient in the throes of delirium would mention physician aid-in-dying, but she said that she does not consider that a serious request. Patients must be consistent and convincing in order to receive a prescription for aid-in-dying, Ganzini said. She also argued that there should be better systematic screening in Oregon for who should be referred to a mental health professional. For instance, Patient Health Questionnaire 9 is a tool that could be used to screen individuals for signs of depression and referral to a psychiatrist. Back added that in addition to simple mental health screens, there is more to learn about what people may be experiencing at the end of life—that is, not quite depression, but perhaps demoralization syndrome or a complicated adjustment reaction. Katrina Hedberg, a health officer and state epidemiologist with the Oregon Health Authority, also noted the limitations in the 5 percent mental health referral statistic and said that there is much more to know about patients who are excluded from the request process, but Oregon does not collect data on this (see Chapter 3 for more information about Oregon's data collection).

### Pain and Suffering

Courtney Campbell, the Hundere Professor of Religion and Culture at Oregon State University, said that the prevention of pain and suffering is often cited as a reason why physician-assisted death should be an option but that the empirical research does not indicate that patients are requesting physician-assisted death for this reason. Ganzini clarified that her research indicates that patients request physician-assisted death to avoid anticipated pain and suffering in the future, but not to relieve pain and suffering they are experiencing at the time of the request (Ganzini et al., 2009). She indicated that very sick people usually do not want to participate in research and therefore it could be a limitation of this research that it includes a healthier population with fewer symptoms. In any case, Ganzini reflected that it is a negative view of the dying process and the

fear of what will happen in the future that is the primary motivator for those requesting aid-in-dying.

Dan Diaz of Compassion & Choices described an experience of his wife, Brittany Maynard (see Chapter 3), and said that it was her fear of pain that led her to request the aid-in-dying process. Diaz explained that Brittany's fear of pain manifested as her disease progressed in the form of more frequent and severe seizures, the inability to sleep for days, and intense nausea and vomiting. Data indicate that loss of autonomy is a more important factor than fear of pain for those requesting aid-in-dying, Diaz said. He said that loss of autonomy is a significant fear and should not be diminished because it does not fit in the category of a current experience of pain.

Back said that it is important to make a closer examination of the reasons why patients do not feel reassured that pain, suffering, and potential loss of autonomy cannot be managed at the end of life. Sulmasy suggested that if the health care system is not delivering the care that patients need in order to feel reassured that they will have their symptoms controlled, then the obligation is to fix the health care system. Patients should have access to quality palliative care to provide that reassurance that these symptoms can, in large part, be addressed, Sulmasy said.

Ganzini suggested that when patients in Oregon make a request for physician aid-in-dying, they are offered hospice if they are not already enrolled in it. She reflected that the unique services hospice can provide go far beyond traditional pain control and offer many ways to maintain control at the end of life.

## REFERENCES

American Psychiatric Association. 2014. *Diagnostic and statistical manual of mental disorders,* 5th ed. Delhi, India: CBS Publishers & Distributors.

Applebome, P. 1989. Judge rules quadriplegic can be allowed to end life. *The New York Times*, September 7, A16.

Armontrout, J., D. Gitlin, and T. Gutheil. 2016. Do consultation psychiatrists, forensic psychiatrists, psychiatry trainees, and health care lawyers differ in opinion on gray area decision-making capacity cases? A vignette-based survey. *Psychosomatics* 57(5):472–479.

Bannink, M., A. R. Van Gool, A. van der Heide, and P. J. van der Maas. 2000. Psychiatric consultation and quality of decision making in euthanasia. *Lancet* 356(9247):2067–2068.

Berg, J. W., P. S. Appelbaum, and T. Grisso. 1996. Constructing competence: Formulating standards of legal competence to make medical decisions. *Rutgers Law Review* 48(2):345–371.

Boer, T. A. 2017. Does euthanasia have a dampening effect on suicide rates? Recent experiences from the Netherlands. *Journal of Ethics in Mental Health* 9(Special Theme Issue II).

Brody, J. E. 2007. Tough question to answer, tough answer to hear. *The New York Times*, March 6, F9.

Burton, C. Z., E. W. Twamley, L. C. Lee, B. W. Palmer, D. V. Jeste, L. B. Dunn, and S. A. Irwin. 2012. Undetected cognitive impairment and decision-making capacity in patients receiving hospice care. *American Journal of Geriatric Psychiatry* 20(4):306–316.

Cairns, R., C. Maddock, A. Buchanan, A. S. David, P. Hayward, G. Richardson, G. Szmukler, and M. Hotopf. 2005. Reliability of mental capacity assessments in psychiatric inpatients. *British Journal of Psychiatry* 187:372–378.

Callinan, K. 2017. People should have choices as their life is ending (commentary). *MassLive*, December 26.

Capron, A. M. 1996. Legalizing physician-aided death. *Cambridge Quarterly of Healthcare Ethics* 5(1):10–23.

Center for Bieothics & Human Dignity. n.d. *Theo A. Boer*. https://cbhd.org/content/theo-boer-phd (accessed March 1, 2018).

Christakis, N. A., and E. B. Lamont. 2000. Extent and determinants of error in doctors' prognoses in terminally ill patients: Prospective cohort study. *BMJ* 320(7233):469–472.

Colorado Medical Society. 2016. *Physician-assisted death: Polling shows a divided membership*. http://www.cms.org/communications/physician-assisted-death-polling-shows-a-divided-membership (accessed April 25, 2018).

Compassion & Choices. 2017. *Compassion & Choices launches PSA with Mexican actor Mauricio Ochmann*. https://www.compassionandchoices.org/compassion-choices-launches-psa-with-mexican-actor-mauricio-ochmann (accessed April 25, 2018).

Compassion & Choices. 2018. *Physician support for medical aid in dying is strong*. https://www.compassionandchoices.org/wp-content/uploads/2018/03/FS-Medical-Professional-Associations-that-Recognize-Medical-Aid-in-Dying-3.02.18-1.pdf (accessed April 25, 2018).

Creighton, C., J. Cerel, and M. P. Battin. 2017. *Statement of the American Association of Suicidology: "Suicide" is not the same as "physician aid in dying."* http://www.suicidology.org/Portals/14/docs/Press%20Release/AAS%20PAD%20Statement%20Approved%2010.30.17%20ed%2010-30-17.pdf?ver=2017-10-30-230833-020 (accessed March 2, 2018).

Curlin, F. A., C. Nwodim, J. L. Vance, M. H. Chin, and J. D. Lantos. 2008. To die, to sleep: U.S. physicians' religious and other objections to physician-assisted suicide, terminal sedation, and withdrawal of life support. *American Journal of Hospice and Palliative Care* 25(2):112–120.

Doernberg, S. N., J. R. Peteet, and S. Y. Kim. 2016. Capacity evaluations of psychiatric patients requesting assisted death in the Netherlands. *Psychosomatics* 57(6):556–565.

Doughty, S. 2014. Don't make our mistake: As assisted suicide bill goes to Lords, Dutch watchdog who once backed euthanasia warns UK of "slippery slope" to mass deaths. *The Daily Mail*, July 9.

Dugan, A. 2015. In U.S., support up for doctor-assisted suicide. *Gallup News*, May 27.

Dugdale, L. S., and D. Callahan. 2017. Assisted death and the public good. *Southern Medical Journal* 110(9):559–561.

Eckstein, L., and S. Y. H. Kim. 2017. Criteria for decision-making capacity: Between understanding and evidencing a choice. *Journal of Law and Medicine* 24(3):678–694.

Etchells, E., P. Darzins, M. Silberfeld, P. A. Singer, J. McKenny, G. Naglie, M. Katz, G. H. Guyatt, D. W. Molloy, and D. Strang. 1999. Assessment of patient capacity to consent to treatment. *Journal of General Internal Medicine* 14(1):27–34.

Fandl, J. 2017. Physician's group endorses medical aid-in-dying legislation. *The Legistlative Gazette*, July 25.

Frye, J., and S. J. Youngner. 2016. A call for a patient-centered response to legalized assisted dying. *Annals of Internal Medicine* 165(10):733–734.

Ganzini, L., D. S. Fenn, M. A. Lee, R. T. Heintz, and J. D. Bloom. 1996. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *American Journal of Psychiatry* 153(11):1469–1475.

Ganzini, L., G. B. Leong, D. S. Fenn, J. A. Silva, and R. Weinstock. 2000. Evaluation of competence to consent to assisted suicide: Views of forensic psychiatrists. *American Journal of Psychiatry* 157(4):595–600.

Ganzini, L., E. R. Goy, and S. K. Dobscha. 2009. Oregonians' reasons for requesting physician aid in dying. *Archives of Internal Medicine* 169(5):489–492.

Garrison, M. 2007. The empire of illness: Competence and coercion in health-care decision making. *William & Mary Law Review* 49(781):781–843.

Gonzalez-Portillo, P. A. 2017. The power of an anchorman known as Jorge. *Compassion & Choices Magazine*. https://www.compassionandchoices.org/wp-content/uploads/2017/10/2017-Fall-Magazine-online-9.27.17.pdf (accessed April 25, 2018).

Gorsuch, N. M. 2006. *The future of assisted suicide and euthanasia*. Princeton, NJ: Princeton University Press.

Grisso, T., and P. S. Applebaum. 1998. *Assessing competence to consent to treatment: A guide for physicians and other health professionals*. New York: Oxford University Press.

Huerta, D. 2017. Voter-approved death with dignity laws threatened by Congress. *The Mercury News*, July 28.

Humphry, D., and M. Clement. 2000. *Freedom to die: People, politics, and the right-to-die movement*. New York: St. Martin's Press.

Jones, D. A., and D. Paton. 2015. How does legalization of physician-assisted suicide affect rates of suicide? *Southern Medical Journal* 108(10):599–604.

Kamisar, Y. 1958. Some non-religious views against proposed "mercy-killing" legislation. *Minnesota Law Review* 42(6):969–1042.

Keown, I. J. 2018. *Euthanasia, ethics and public policy*. 2nd ed. Cambridge, UK: Cambridge University Press.

Kim, S. Y. H. 2010. *Evaluation of capacity to consent to treatment and research*. New York: Oxford University Press.

Kim, S. Y., P. S. Appelbaum, H. M. Kim, I. F. Wall, J. A. Bourgeois, B. Frankel, K. C. Hails, J. R. Rundell, K. M. Seibel, and J. H. Karlawish. 2011. Variability of judgments of capacity: Experience of capacity evaluators in a study of research consent capacity. *Psychosomatics* 52(4):346–353.

Kim, S. Y., R. G. De Vries, and J. R. Peteet. 2016. Euthanasia and assisted suicide of patients with psychiatric disorders in the Netherlands, 2011 to 2014. *JAMA Psychiatry* 73(4):362–368.

Li, M., S. Watt, M. Escaf, M. Gardam, A. Heesters, G. O'Leary, and G. Rodin. 2017. Medical assistance in dying—implementing a hospital-based program in Canada. *New England Journal of Medicine* 376(21):2082–2088.

Markoe, L. 2016. Washington, DC, approves "Death with Dignity Act." *National Catholic Reporter*, November 2.

Maryland State Medical Society. 2016. *Results of MedChi survey on assisted suicide/aid in dying—2016*. http://www.medchi.org/News-and-Publications/Surveys (accessed April 25, 2018).

Marzuk, P. M., K. Tardiff, C. S. Hirsch, A. C. Leon, M. Stajic, N. Hartwell, and L. Portera. 1993. Increase in suicide by asphyxiation in New York City after the publication of *Final Exit*. *New England Journal of Medicine* 329(20):1508–1510.

Marzuk, P. M., K. Tardiff, and A. C. Leon. 1994. Increase in fatal suicidal poisonings and suffocations in the year *Final Exit* was published: A national study. *American Journal of Psychiatry* 151(12):1813–1814.

Massachusetts Medical Society. 2017. *Massachusetts Medical Society adopts several organizational policies at interim meeting*. http://www.massmed.org/News-and-Publications/MMS-News-Releases/Massachusetts-Medical-Society-adopts-several-organizational-policies-at-Interim-Meeting/#.WuDUIC7wZEb (accessed April 25, 2018).

Miller, D. G., and S. Y. H. Kim. 2017. Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: A qualitative review of review committee judgements. *BMJ Open* 7(10):e017628.

Nelson, R. M., T. Beauchamp, V. A. Miller, W. Reynolds, R. F. Ittenbach, and M. F. Luce. 2011. The concept of voluntary consent. *American Journal of Bioethics* 11(8):6–16.

O'Brien, A. 2018. Suicide rate is up 1.2 percent according to most recent CDC data (year 2016). *Lifesaver Blog*. American Foundation for Suicide Prevention. https://afsp.org/suicide-rate-1-8-percent-according-recent-cdc-data-year-2016 (accessed April 23, 2018).

Oregon Health Authority. 2018. *Oregon Death with Dignity Act 2017 data summary.* Salem: Oregon Health Authority.

Rabkin, J., R. Goetz, J. M. Murphy, P. Factor-Litvak, and H. Mitsumoto. 2016. Cognitive impairment, behavioral impairment, depression, and wish to die in an ALS cohort. *Neurology* 87(13):1320–1328.

*Red Latina*. 2017. National Hispanic Council on Aging endorses medical aid-in-dying laws. October 26.

Reisman, N. 2018. Latino group back aid-in-dying bill. *NY State of Politics*, February 15.

Sessums, L. L., H. Zembrzuska, and J. L. Jackson. 2011. Does this patient have medical decision-making capacity? *JAMA* 306(4):420–427.

Seyfried, L., K. A. Ryan, and S. Y. Kim. 2013. Assessment of decision-making capacity: Views and experiences of consultation psychiatrists. *Psychosomatics* 54(2):115–123.

Silveira, M. J., S. Y. Kim, and K. M. Langa. 2010. Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine* 362(13):1211–1218.

Smietana, B. 2016. Most Americans say assisted suicide is morally acceptable. *LifeWay*, December 6.

Sorger, B. M., B. Rosenfeld, H. Pessin, A. K. Timm, and J. Cimino. 2007. Decision-making capacity in elderly, terminally ill patients with cancer. *Behavioral Sciences and the Law* 25(3):393–404.

Sugarman, J., and D. P. Sulmasy. 2010. *Methods in medical ethics*. 2nd ed. Washington, DC: Georgetown University Press.

Trachtenberg, A. J., and B. Manns. 2017. Cost analysis of medical assistance in dying in Canada. *Canadian Medical Association Journal* 189(3):E101–E105.

UN (United Nations). 1948. The Universal Declaration of Human Rights. General Assembly resolution 217A, adopted December 10, 1948.

Wagner, B., J. Muller, and A. Maercker. 2012. Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide. *European Psychiatry* 27(7):542–546.

# 3

# Experiences with and Reflections on Physician-Assisted Death in the United States

**Key Messages Presented by Individual Speakers/Participants**

- In Oregon, a significant percentage of patients who asked for physician-assisted death and whose physicians implemented a substantive palliative intervention or provided a referral to hospice later changed their minds about wanting physician aid-in-dying. (Ganzini)
- The most important reasons that Oregon patients request physician aid-in-dying is to maintain control; having concerns regarding a loss of independence, future physical symptoms, and the inability to care for oneself; not wanting to be cared for by others; and wanting to die at home. (Ganzini)
- The Oregon Death with Dignity Act requires the state to collect data focused on monitoring compliance with specific provisions of the law. The state does not collect information about the conversations between physicians and patients or about the decision-making process concerning physician-assisted death. (Hedberg)
- A terminally ill person who applies for physician-assisted death is not choosing between living and dying, but between two different methods of dying. (Diaz)
- Health systems that provide a navigator make a significant difference to patients in terms of working through the bureaucratic complexities of the law. (Starks)

- In some cases of physician-assisted death, family members see themselves as project managers, which is not a job they always want to have. On the day of death, family members can be so fixated on that role that they cannot be fully present with their loved ones at the end of their lives. (Starks)
- Allowing organizations to prohibit their employees from participating in physician-assisted death is attentive to the notion of "organizational conscience," but also creates an access barrier for patients seeking aid-in-dying. (Wynia)
- The challenges physicians face are much broader than simply grappling with whether or not to write a prescription for lethal medication; they include determining patients' eligibility and helping patients navigate the bureaucratic process. (Buchbinder)
- It is unclear if the lower rate of use of physician-assisted death among low socioeconomic status groups reflects unequal access, lack of information, or a less of a preference for aid-in-dying among these groups. (Buchbinder)

NOTE: These points were made by the individual speakers/participants identified above. They are not intended to reflect a consensus among workshop participants. The statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

## THE OREGON EXPERIENCE

Oregon's Death with Dignity Act first passed by popular vote—51 to 49 percent—in 1994 but was not enacted until 1997 after a series of legal challenges and a second vote. For 14 years Oregon remained the only U.S. state to have legalized physician aid-in-dying, and Linda Ganzini, a professor of psychiatry and medicine at Oregon Health & Science University and associate director of the Health Services Research and Development Center of Innovation in the Veterans Affairs (VA) Portland Health Care System,[1] said she had thought the law would always be "one of these quirky Oregon things." That changed, however, when Washington State passed a nearly identical law in 2008, followed by Vermont in 2013, and

[1] The views expressed in these workshop proceedings are those of Dr. Ganzini and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the U.S. government.

California, Colorado, and Washington, DC, more recently.[2] By Ganzini's calculation, almost 60 million people now live in U.S. jurisdictions in which physician aid-in-dying is legal. In addition, as a result of a judicial decision, Montana does not prosecute physician aid-in-dying for competent, terminally ill patients.

## Statistics and Research Results on Physician-Assisted Death in Oregon

*Linda Ganzini*
*Professor of Psychiatry and Medicine*
*Oregon Health & Science University*

*Katrina Hedberg*
*Health Officer and State Epidemiologist*
*Oregon Health Authority*

The Oregon law, as well as others modeled on it, allows a competent, terminally ill patient to receive a lethal prescription from a physician for self-administration. A second physician must confirm that the patient is both competent and terminally ill, and the patient must be informed of all feasible alternatives, such as hospice care. If there is concern that a mental illness such as depression is affecting the decision, the patient must be evaluated by a mental health professional. Physicians and other health care providers are not required to participate. The law does not allow for lethal injection or for aid-in-dying to occur as a result of a request in an advance directive. Physicians who prescribe the medication are required to notify the state and provide documentation that the legal requirements have been met.

Over the past 20 years, physicians have written 1,967 prescriptions, and 1,275 people—65 percent—have taken those medications to hasten their deaths, said Katrina Hedberg, a health officer and state epidemiologist with the Oregon Health Authority's Public Health Division. On an annual basis, approximately 0.2 percent of deaths in Oregon result from taking prescribed lethal medications. The median age of those taking the medication is 72, with the large majority over age 55 (Oregon Health Authority, 2018).

More than three-quarters (78 percent) of those who die by lethal prescription have cancer as the underlying cause of death, Hedberg said.

[2] After the dates of the workshop, Hawaii passed a law in April 2018 legalizing physician-assisted death. Our Care, Our Choice Act. H.B. 2739, 29th Legislature, State of Hawaii (April 2018).

Amyotrophic lateral sclerosis (ALS) patients have the highest rate of participation, at nearly 440 per 10,000 people (Hedberg and New, 2017). Physicians report that approximately 90 percent of the individuals who died from lethal medication said their end-of-life concerns were losing autonomy and being unable to participate in activities that make life enjoyable. More than 75 percent said loss of dignity was a major concern, and almost half feared losing bodily control. More than 40 percent worried they would be a burden to their family, 26 percent were concerned about inadequate pain control, and under 4 percent had financial concerns (Oregon Health Authority, 2018).

Among individuals with the same underlying disease, individuals with college or graduate degrees are far more likely to have a physician-assisted death (Hedberg and New, 2017), Hedberg said. Between 2000, the first year that data were collected, and 2017, 374 physicians, or 0.6 percent of all licensed physicians in Oregon, wrote at least one prescription (with 85 being the most). Twenty-two physicians have been reported to the Oregon Medical Board for incorrect documentation, incomplete written consent, lack of two witnesses, or not complying with the mandated waiting period; in each of these instances, the medical board found that the physicians had acted in good-faith compliance with the law.

The referral rate for psychological evaluation has been approximately 5 percent, but it has been declining (Hedberg and New, 2017). Hedberg said that the percentage of deaths at which the health care provider was present has also declined since 2000 (Hedberg and New, 2017). Nearly 90 percent of patients were in hospice at the time they took the lethal medication. The patient's home, followed by assisted living facilities, were the two most common locations of death (Oregon Health Authority, 2018). The median time from ingestion to death was 25 minutes, with a range of 1 minute to 104 hours, Hedberg said. Seven people regained consciousness, which Hedberg said reflects the fact that the medications do not work uniformly (Oregon Health Authority, 2018).

One of the first surveys that Ganzini and her colleagues conducted—in 1999—went to more than 4,000 Oregon physicians, of which 2,649 responded (Ganzini et al., 2000b). By then, 143 physicians had received a request for a lethal dose of medication, of which one in six resulted in the physician writing the prescription. At the time of the request, almost one-third of the patients were already in hospice, three-quarters had a life expectancy of less than 6 months, and 59 percent were confined to a bed or chair for over half of their waking hours. In almost half of the cases, she said, the physician responded to the request by implementing a substantive palliative intervention such as treating pain, referring to hospice, or referring the patient to see a mental health professional. Nearly half of the Oregonians with substantive interventions changed their mind about

physician-assisted death, compared with 15 percent of those individuals who did not receive those interventions (Ganzini et al., 2000a). The intervention most likely to result in a patient withdrawing the request for aid-in-dying was referral to hospice. Small-town physicians were less likely to write a prescription for lethal medication, as were physicians whose patients viewed themselves as a burden or had symptoms of depression. Physicians were more likely to prescribe if the patient was enrolled in hospice and wanted control over his or her death. Ganzini and her colleagues found that 34 percent of physicians were willing to prescribe lethal medication (Ganzini et al., 2001).

In all of her studies, Ganzini measures religiousness on a scale of 1 to 10, where 10 means religion is very important in the respondent's life and 1 means religion is not important in the respondent's life. In Oregon, hospice nurses and caregivers of ALS patients and cancer patients had an average score of 6 to 7, but patients requesting physician aid-in-dying had an average score of 2.3, the lowest score of any group she and her team have measured. This finding, she said, may indicate that religiousness protects one from pursuing physician aid-in-dying and is likely one reason that Oregon was the first state to pass a physician-assisted death law, given that it is among the least religious of all states. Ganzini added that the strongest predictor of who among the terminally ill will request physician aid-in-dying was a low score on a measure of spirituality that combines meaning, hope, and purpose in one's life (Smith et al., 2015). Another correlate was the patient having a dismissive attachment style, which is characterized by lifelong values of self-sufficiency and independence (Oldham et al., 2011).

One concern about physician aid-in-dying is that it is a form of suicide, Ganzini said. Given that mental disorders, and particularly depression, are the most important risk factors for suicide, a question to answer is how much depression compels patients to pursue physician aid-in-dying, said Ganzini. Ganzini said that the results of her research are mixed. In a study of Oregon hospice practitioners, Ganzini and colleagues asked social workers to rate their clients' depression on a scale of 1 to 5, where 5 denotes a very important reason for requesting physician aid-in-dying. The practitioners interviewed had a great deal of clinical experience in assessing depression in hospice patients and rated depression as an average of 1: they did not feel that patients were asking for physician aid-in-dying because of depression (Ganzini et al., 2002). However, a study of requesting patients found that one in four met the criteria for significant clinical depression, although about half of those patients did not feel that depression was influencing their request (Ganzini et al., 2009a). Of the 18 patients in the study who received lethal prescriptions, 3 had clinical depression but had not had a mental health evaluation, although

2 of those said they did not believe depression was influencing their decision. The third patient was successfully treated for depression and still chose physician aid-in-dying. Ganzini said that the results, in total, leave unanswered questions regarding the role of depression in requests for lethal prescriptions.

Ganzini's research has shown that the desire to maintain control is among the strongest reasons that patients request physician aid-in-dying. Also rating highly, she said, were the loss of independence, future physical symptoms and inability to care for one's self, not wanting to be cared for by others, and wanting to die at home (Ganzini et al., 2009a). Studies that included qualitative interviews with physicians and hospice nurses about their patients have supported this finding (Ganzini et al., 2000a, 2003; Miller et al., 2004).

Suicide in a family can be associated with a sense of shame, rejection, and stigma on the part of family members, but family members of physician-assisted death patients scored no differently on depression, prolonged grief, the peace they felt at the end of the patient's life, or other measures of mental health and grief than family members of people who died of natural causes. In fact, Ganzini said, the families of patients who requested physician aid-in-dying felt much more prepared for the death of their loved ones and felt that the patient's end-of-life preferences were honored. Ganzini said that these outcomes appear different than in the case of suicide (Ganzini et al., 2009b).

In summary, Ganzini said, the primary reason Oregonians request physician aid-in-dying is to increase their sense of control and avoid dependence on others. Qualitative interviews show that this is a lifelong value and not something that occurs just at the time of a terminal illness. Patients are also more motivated to request physician aid-in-dying because of worries about future symptoms than because of worries about the symptoms they are experiencing at the time of their request. While one in four of requesting Oregonians studied have had clinical depression, Ganzini said it is unclear how this mental disorder influences the request. Finally, pursuing physician aid-in-dying is not associated with an increased risk of adverse mental health outcomes in family members (Ganzini et al., 2009b).

### Data Collection

Oregon's law, Hedberg said, requires the state to monitor compliance and issue an annual report containing data collected up to the point a prescription is written for a patient requesting physician-assisted death. The law does not address what happens once the prescribing physician files notification with the state that a prescription has been

written and the law does not mandate collecting data on conversations between physicians and their patients leading up to the writing of a prescription. The law does not include any requirements for who needs to be present at the time of ingestion, for the prescribing physician to reevaluate the patient for mental competency prior to ingestion, or to monitor the patient until death. Data on when a patient eventually dies are determined by matching the patient who received a prescription with the death certificates, which also provide some information on demographics, education, and underlying illness, Hedberg said. Although death certificates are not the best source for demographic information, she said, they are the nationwide standard source of such data. Hedberg said that in Oregon, prescribing physicians are required to complete a patient follow-up form, on which they indicate whether the patient ingested the medications, and provide information about the circumstances surrounding the death.

During the discussion period a workshop participant noted that physician-assisted death laws specify that it is illegal for physicians to note in the death certificate that the cause of death is physician-assisted death and questioned the intellectual integrity of this requirement. Neil Wenger of the University of California, Los Angeles, said that some physicians in California have expressed a similar concern that they must write untruthful things on death certificates in cases of physician-assisted death. Timothy Quill of the University of Rochester School of Medicine said that the underlying disease (e.g., cancer, heart disease) is reported on the death certificate. In domains similar to physician-assisted death—withdrawal of treatment or palliative sedation—the same is true in that the underlying disease is most often reported as the cause of death, Quill said.

Hedberg spoke of the importance of balancing the right to privacy of a patient who is dying, and the associated confidentiality issues, with the need for society to understand discussions at the end of life and decisions about participating in assisted death. While the physicians report that patients have met the qualifications outlined in Oregon's law, they do not report specific details of their evaluation, said Hedberg. For example, data elements not included under the requirements of the law include how the diagnosis and prognosis were made and how the patient's mental capacity was ascertained. Hedberg said that data are also not collected on patients who were denied their request and the reasons for that denial.

During the discussion, John Kelly of Not Dead Yet shared reports of disabled and terminally ill individuals believed to be coerced or involuntarily euthanized in Oregon and asked if the state could include instances of violations of the law in their annual reporting. In response, Hedberg

said she recognized that many would like to see more information available through the state's oversight mechanism but that as currently written, the statute is silent on any data collection efforts in the period after a prescription is written. She clarified that the information about potential abuses of the law reported in the blogosphere is not seen by the Oregon Health Authority and that therefore the members of the authority do not have a role in potential criminal charges related to the act. Hedberg said that a certain degree of tension exists in that many advocates of physician-assisted death want less reporting and data collection, whereas opponents want more.

Dan Diaz of Compassion & Choices said that any requirement to collect data on physician aid-in-dying should balance the privacy of patients and families. Additional data collection efforts should not burden patients or families, or intrude unnecessarily in their lives, Diaz said, and in the end, data collection efforts should benefit the patient.

### Surveys of Patients, Families, and Health Care Practitioners

To partially remedy the shortcomings of Oregon's official reporting system, Ganzini has conducted a series of research surveys that collect information directly from patients and families. The greater detail in the resulting data is useful for hypothesis testing, she said, although she acknowledged that not everyone invited to participate returns the surveys, so there could be a selection bias which might limit generalizability. She noted, too, that these surveys were administered 10 to 20 years ago and that it is possible the data have changed since then.

In addition to research surveys, Ganzini has conducted qualitative research interviews which produced vivid descriptions of participants' experiences. She said that these interviews can be used to generate hypotheses and can support quantitative data, although they lack generalizability and have a risk of bias (Dobscha et al., 2004; Ganzini et al., 2003; Harvath et al., 2006). Ganzini studied all physicians in Oregon eligible to prescribe under the law and found that 5 percent of the state's physicians had received a request for physician aid-in-dying by 1999 (Ganzini et al., 2000b). Another early study of hospice nurses and social workers found that almost one-third of respondents had cared for a client who had received a lethal prescription (Ganzini et al., 2002). An advantage of studying that particular population, Ganzini explained, is that hospice nurses and social workers see patients more frequently than physicians and have more discussions with them in the last few weeks of life. All of these surveys, Ganzini said, had response rates of more than 65 percent, making it more likely that the results are generalizable. Other studies she

has conducted included measuring depression, hopelessness, social support, burden to others, religiousness, and reasons for request in 56 Oregonians who had explicitly requested physician-assisted death (Ganzini et al., 2009a) and interviewing 95 family members of 83 Oregonians who had requested physician-assisted death; interviews took place an average of 14 months after their loved one's death (Ganzini et al., 2009b).

Surveys of Oregon health care providers, some of which were conducted more than 20 years ago, found that physicians and hospice nurses were divided in their support for the law, with about half supporting it, one-third opposing it, and the rest holding a neutral opinion. Hospice social workers tended to be much more supportive of the option, which Ganzini said might reflect the focus on client autonomy in their education (Miller et al., 2004). Hospice chaplains were surprisingly divided, she said, with a similar number supporting and opposing the law, but 54 percent had worked with a requesting patient (Carlson et al., 2005). Psychiatrists have a core professional role in preventing suicide, she noted, but over half supported this law, and psychologists overwhelmingly supported the law (Fenn and Ganzini, 1999b; Ganzini et al., 1996). Table 3-1 describes the attitudes of various Oregon health care practitioners toward Oregon's Death with Dignity Act or physician-assisted death as collected through different surveys.

Her team's study of the attitudes of other health care practitioners found that only 3 percent of hospice nurses (Miller et al., 2004) and 14 percent of hospice chaplains would actively oppose a client's choice for physician aid-in-dying (Carlson et al., 2005). None of the chaplains surveyed would transfer a patient who received a lethal prescription to another chaplain, while 12 percent of hospice nurses said they would transfer such a patient to another hospice nurse (Carlson et al., 2005; Miller et al., 2004). Ganzini said she believes that these numbers reflect the increased focus on non-abandonment among hospice providers. The most recent figures show that 90 percent of patients who die by physician-assisted death in Oregon are enrolled in hospice (Oregon Health Authority, 2018). Ganzini said that this is important because there is general agreement that physician aid-in-dying should be the option of last resort after other palliative interventions have failed.

Dan Diaz, Latino Leadership Council, Compassion & Choices, shared the experience of his wife, Brittany Maynard, in seeking access to medical aid-in-dying (see Box 3-1).

**TABLE 3-1** Oregon Health Care Practitioners' Attitudes Toward the Oregon Death with Dignity Act or Physician-Assisted Death

| Attitude Toward Oregon Death with Dignity Act or Physician-Assisted Death | Generalist Physicians N = 2,641 (Ganzini et al., 2001) | Hospice Nurses N = 306 (Miller et al., 2004) | Hospice Social Workers N = 85 (Miller et al., 2004) | Hospice Chaplains N = 50 (Carlson et al., 2005) | Psychiatrists N = 307 (Ganzini et al., 1996) | Psychologists N = 423 (Fenn and Ganzini, 1999a) |
|---|---|---|---|---|---|---|
| Support | 51% | 48% | 72% | 40% | 56% | 78% |
| Oppose | 32% | 36% | 13% | 42% | 44% | 22% |
| Neutral | 17% | 16% | 15% | 18% | | |

SOURCES: Ganzini presentation, February 12, 2018. Data from Carlson et al., 2005; Fenn and Ganzini, 1999a; Ganzini et al., 1996, 2001; and Miller et al., 2004.

**BOX 3-1**
**Brittany Maynard and Dan Diaz**

Dan Diaz told the story of how a few months after he and Brittany Maynard were married in September 2012, Brittany starting having headaches that would wake her in the middle of the night. On New Year's Day 2014, Diaz had to take his wife to the hospital because the pain was too intense. A magnetic resonance imaging (MRI) scan revealed that Brittany had a large, incurable brain tumor. After a 7-hour surgery to "de-bulk" the tumor in order to alleviate her immediate symptoms, Brittany, who was 29 years old, was given a 3- to 5-year prognosis. Unfortunately, a follow-up MRI 2 months later showed that the tumor had returned and was growing aggressively, indicative of glioblastoma multiforme and a prognosis of 6 months.

Brittany was determined to live, Diaz said, and the two of them researched every available treatment option, both in the United States and abroad. One day, Brittany told her husband that she was not afraid of death—words that he knew were not just lip service—but that she was afraid of suffering, especially since she was going to die eventually. From personal experience, with both of them having seen people close to them die horrible deaths from brain cancer, Brittany and Diaz knew what was coming, and Brittany wanted to die peacefully, not in pain. She brought up the topic of medical aid-in-dying, which was not legal at the time in their home state of California, and, as the symptoms progressed, Diaz took a leave of absence and the two moved to a house they rented in Portland. "We said good bye to our friends and family, packed half of our house in California into a U-Haul, and drove 600 miles north. Nobody should have to go through that, leaving home like that after being told that you have 6 months to live."

After establishing residence in Oregon and finding a new medical team, Brittany applied for, qualified, and was granted the prescription for medical aid-in-dying in May 2014. Brittany put the medication in a cupboard and focused on living life. She went to Yellowstone National Park with Diaz and hiked glaciers in Alaska with a friend. She and Diaz spent time in Olympic National Park and took a helicopter tour of the Grand Canyon, all the while hoping that Brittany would be accepted into any clinical trial that offered a glimmer of hope.

Having the medication emboldened Brittany to fight, for it alleviated the fear she had of suffering at the end of her life. Diaz stressed this because there are those who suggest that if a person applies for this program, he or she has given up. "That could not be further from the truth," he said. Brittany died gently on November 1, 2014, a full 6 months after receiving the prescription. "Within 5 minutes of taking the medication, she fell asleep very peacefully," Diaz recounted. "Within 30 minutes, her breathing slowed to the point where she passed away. That was the gentle dying process that this program afforded her. That is not the dying process she would have experienced if that brain tumor would have continued to run its course."

To Diaz, the term physician-assisted suicide is an insult to terminally ill patients. "My wife Brittany wanted to live. A suicidal person wants to die," he said. "Brittany was not depressed, despondent, or making irrational decisions, all of those being the characteristics of a person who is suicidal." In his opinion, he said, a terminally ill person who applies for this program is not choosing between

*continued*

**BOX 3-1 Continued**

living and dying. "The living part is no longer on the table," Diaz said. "That is not an option. They are only choosing between two different methods of dying. One is gentle, peaceful. The other would be struggling and in pain."

One last thing that Diaz shared came straight from Brittany. "Medical aid-in-dying is not at odds with palliative care or hospice," he said. In fact, Brittany had what he called a wonderful palliative care team at Oregon Health & Science University.

SOURCE: As presented by Dan Diaz, February 12, 2018.

## OTHER U.S. EXPERIENCES

### Washington

*Helene Starks*
*Associate Professor of Bioethics and Humanities*
*University of Washington*

More than 20 years ago, Helene Starks, an associate professor of bioethics and humanities and an adjunct associate professor of health services, family medicine, and pediatrics at the University of Washington, conducted a study in which she and her research team asked patients and families in Washington, where physician-assisted death was still illegal, and in Oregon, where physician-assisted death had recently been approved, about their experiences in helping family members with terminal illnesses hasten their deaths (Back et al., 1996, 2002; Starks et al., 2005, 2007). She and her colleagues interviewed 35 families, and in the 12 cases where they could recruit the patient while he or she was still alive, they followed the patient until death. In all cases, they followed the families for another year to gain some insight on their bereavement experiences.

This study found that patients do not make this decision quickly and that there are three basic concerns that patients take into account when considering physician-assisted dying as a serious option: (1) the enduring diminishments that come with terminal illness; (2) the exhaustion that comes with the process of dying and living with the side effects of treatment, including pain medication; and (3) the more existential threat of a person losing his or her sense of self (Pearlman et al., 2005). In addition to this "triple threat," patients also have fears about what the trajectory

of their death will entail, based either on past experiences with others' death or on what they think or know about the course of their own illness.

Given that the procedure was illegal in Washington at the time of the study, the patients who wanted to hasten their own deaths had to accumulate a lethal dose of medication on their own. Starks analyzed the reasons and triggers for the eventual timing of the patients' deaths. The research team organized the cases based on their own estimates of the patients' prognosis given the patients' clinical situation (Starks et al., 2005). Those individuals with days to 1 week to live waited to take the medication until the day they were likely to die anyway; for these patients it was a matter of asserting their own control over the disease process and not feeling like a victim of the disease. For those with a longer estimated prognosis, Starks said, the fear of what the future might hold characterized why they chose to die when they did.

Regarding families, Starks said that current laws protect the patient and physician but do not address the concerns of patients' families. People are often told that families should leave the room during discussions about physician aid-in-dying to avoid the possibility of coercion, Starks said, but often these conversations include important education about the process. This means that family members may not be as informed as they could be, even though they are often actively involved with planning and logistics from the beginning. Additionally, in places where the practice is still illegal, family members are often charged with implementing a backup plan in case of a medication failure.

Overall, families have felt very isolated and ill-prepared, especially in places where the practice was illegal, Starks said (Starks et al., 2007). She said that her personal stance toward physician aid-in-dying was originally neutral but that this study swayed her in the direction of legalization because it mandates that people have a protocol and are engaged. In this way, she explained, people are able to access the information that previously they were trying to figure out on their own. She pointed out that assisted death is still happening in places where it is not legal and said that if patients want it, they will find a way.

## California

*Helene Starks*
*Associate Professor of Bioethics and Humanities*
*University of Washington*

Starks and colleagues at the University of California, San Francisco, are now conducting a study in California similar to the one she conducted in Washington two decades ago. From the patients and families they have

spoken with so far, they have learned that health systems that provide a navigator make a significant difference for patients and families in terms of working through the bureaucratic complexities of the law. There are problems, however, with the interpretation of what counts as a patient's first request. Some patients consider the first request to be when they are given the news that they are out of options and they say they want to start the death-with-dignity process. However, this request is not always heard by their physicians, and thus, while they believe they have started the process, they find out later that this request was not formally recognized, said Starks.

When physicians stall, said Starks, patients often go outside their health systems to find another physician who will provide the initial approval. When patients are able to access a willing provider inside their system, it is often a consulting physician who is confirming the prognosis, not someone writing the prescription, stated Starks.

Offering lessons from California's experience, Starks said that the process takes time and that very few patients or health systems report that they are able to complete the request process in 15 days. The exceptions, she said, occur with what she has started calling the "destination doctors," practitioners who are providing physician-assisted death either as a specialty within a larger practice or as their sole practice. In a sense, these physicians become self-made navigators who know how to work the system. At the same time, Starks said, she has found that physicians' ambivalence is a factor that slows down the process, particularly with those who have received a request for lethal medication for the first time. Starks has found that what patients want is for physicians to tell them right away if they are ambivalent about aid-in-dying so that the patient has the opportunity to find another provider without delay. Some physicians took weeks to months to decide if they were going to participate, Starks said, which created additional stress for the waiting patients.

Families have told Starks that they see themselves as being project managers, which was not the job they always wanted to have. This is particularly true when it comes to managing the medication. "There is a great deal of distress about what it takes to open 100 Seconal capsules," Starks said. Some family members have reported that on the day of death they were so fixated on their roles as project managers that they could not be fully present with their loved ones during the final moments of their lives. One person told Starks that she felt cheated out of the last couple of minutes because she was helping her family member with the medicine.

## Colorado

*Matthew Wynia*
*Director, Center for Bioethics and Humanities*
*University of Colorado*

In its first year of implementation, 69 Coloradoans received prescriptions for lethal medications from 37 physicians, although little is known about how many individuals picked up or used the medications, said Matthew Wynia, the director of the Center for Bioethics and Humanities at the University of Colorado Anschutz Medical Campus. Like other states with physician aid-in-dying laws, said Wynia, physicians are precluded from noting on the death certificate that the individual died as a result of taking these medications; therefore, it is not possible to truly know how many patients in Colorado died from these drugs. He noted that 96.4 percent of those receiving the prescriptions were white and 87.5 percent lived in the Colorado Springs–Denver–Fort Collins corridor (Colorado Department of Public Health and Education, 2018). While Colorado as a whole is largely white, 30 percent of Denver's population is Latino or Hispanic, so these initial data suggest that racial and ethnic disparities with respect to access may be significant.

One unusual feature of the Colorado statute, said Wynia, is that it allows individual providers, but not organizations, to opt out. Under the terms of statute, organizations are not allowed to tell their physicians or pharmacists that they cannot participate in the law. However, organizations can prohibit patients from taking the lethal medication on their premises in the same way that the state prohibits people from taking these medications in state parks. The provision for organizations stems from lessons that advocates learned from Oregon and other earlier adopters, which is that while allowing organizations to prohibit employees from participating in the program may be respectful of the notion of "organizational conscience," it creates an access barrier for patients. Despite the law, several health systems in Colorado have nevertheless said that they are prohibiting their employees from participating in the end-of-life process, which could eventually prompt a legal challenge. Given the writings of Neil Gorsuch, the newest U.S. Supreme Court member, Wynia suggested that this provision might not survive a court challenge if it were to be heard by the U.S. Supreme Court (Gorsuch, 2006).

## Vermont

*Mara Buchbinder*
*Associate Professor of Social Medicine*
*University of North Carolina at Chapel Hill*

The Patient Choice and Control at End of Life Act was signed into law by Vermont's governor in May 2013, and as of the end of June 2017 paperwork had been submitted for 52 patients who made use of the law (Englander, 2018), said Mara Buchbinder, an associate professor of social medicine and adjunct associate professor of anthropology at the University of North Carolina at Chapel Hill. She said that the law's requirements are nearly the same as those in Oregon.

In her qualitative and ethnographic study conducted between 2015 and 2017, Buchbinder addressed three primary questions: How do ordinary people understand, access, and contest medical aid-in-dying once it is legally authorized? How do health care providers and policy stakeholders accommodate or resist medical aid-in-dying as a new end-of-life practice? What are the ethical challenges for clinical communication and the patient–clinician relationship? To answer those questions, Buchbinder conducted 144 semi-structured interviews of nurses, chaplains, social workers, terminally ill patients, lay caregivers, policy makers and activists, other Vermont residents, and physicians, many of whom had direct experience with Vermont's law either as a prescriber or as a secondary physician. Buchbinder said that because Vermont is so small, she was able to talk to a majority of the prescribers in the state.

Several preliminary findings have emerged from this work, Buchbinder said, although she is still analyzing the results of her interviews. First, the challenges for physicians are much broader than simply grappling with whether to write a prescription and include, among other things, determining patients' eligibility. Physicians, as well as nurses and social workers, assist with all aspects of the bureaucratic process, including finding a second physician to certify eligibility, identifying a pharmacy, and completing the paperwork. Many providers, particularly those in private practices and in more rural areas, reported that they felt isolated while navigating this process, Buchbinder said. In fact, many providers had the sense that they were reinventing the wheel each time they started this process because there were no protocols to follow and there were few experienced colleagues to turn to for guidance. Some providers were able to connect with advocacy organizations for support, such as the Compassion & Choices Doc2Doc program,[3] which enabled them to speak with

[3] For more information, see https://www.compassionandchoices.org/research/doc2doc-program (accessed March 23, 2018).

experienced physicians in other states. Buchbinder said that there are no formal mechanisms in place in Vermont for sharing lessons learned.

Some providers, she said, involved themselves in planning for the death, such as by making contingency plans for possible adverse events. Some doctors and nurses were present at the death to help deal with emergent adverse events or otherwise provide social support, at the patient's request. In addition, even physicians who did not prescribe lethal medication were sometimes involved in these other steps because they felt committed to supporting a patient's wishes and to the ethos of non-abandonment.

Buchbinder said she has been interested in the way that different providers conceptualize this work. Some see it as falling on the spectrum of palliative care and as no different from other clinical services they provide. Other physicians see it as emotionally and morally burdensome, although they were often still grateful for the opportunity to participate. One physician, who had been one of the heavier prescribers, retired early, in part because of the burden of practicing under Vermont's law. Another physician told Buchbinder about a patient who experienced a brutal death during the 15-day waiting period between requests, which left the physician feeling terrible that they had not started the process sooner. This type of timing issue came up repeatedly in her interviews with both providers and family members, Buchbinder said.

In July 2016 a lawsuit was filed by the Vermont Alliance for Ethical Healthcare and the Christian Medical and Dental Association against the Vermont Board of Medical Practice and several other state agencies alleging that Vermont's law entailed an affirmative duty to inform terminally ill patients that the law was an option in their state and therefore that the law violated the constitutional rights of these physicians. The lawsuit was not successful, but it did raise an important ethical question of whether physicians should inform patients about assisted dying laws (Buchbinder, 2017).

Buchbinder said that the physicians and nurses in her study expressed a range of perspectives on who should initiate discussion of aid-in-dying and that some providers reported initiating such a discussion under certain circumstances. Buchbinder noted that we need to be thinking about "circumstances in which it might be ethically permissible for physicians and nurses to inform qualifying patients about aid-in-dying." Buchbinder explained that she did not want to minimize the difficult ethical questions at stake—around the nature of professional responsibility, potential harms to the doctor–patient relationship, and the potential for undue influence—when it comes to talking about physician aid-in-dying. However, she said, it is worth acknowledging that some providers are indeed bringing up this option with their patients and that medical ethics needs to grapple with this.

One reason Buchbinder said she believes it is worth reconsidering the conventional view that communication should always be patient-initiated is that patients who already know about aid-in-dying laws are likely to be more educated. In that case, she said, waiting for patients to initiate a request might create access gaps for patients from less-advantaged populations. On the one hand, waiting for patients to initiate the conversation might appease concerns about the coercion of vulnerable groups to use aid-in-dying. On the other hand, public policies that privilege access for relatively advantaged populations raise justice concerns (Buchbinder, 2017, 2018). Data showing a lower use of aid-in-dying among low socioeconomic status groups might reflect unequal access rather than less of a preference for aid-in-dying among these groups, Buchbinder said (Battin et al., 2007).

## REFERENCES

Back, A. L., J. I. Wallace, H. E. Starks, and R. A. Pearlman. 1996. Physician-assisted suicide and euthanasia in Washington State. Patient requests and physician responses. *JAMA* 275(12):919–925.

Back, A. L., H. Starks, C. Hsu, J. R. Gordon, A. Bharucha, and R. A. Pearlman. 2002. Clinician–patient interactions about requests for physician-assisted suicide: A patient and family view. *Archives of Internal Medicine* 162(11):1257–1265.

Battin, M. P., A. van der Heide, L. Ganzini, G. van der Wal, and B. D. Onwuteaka-Philipsen. 2007. Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on patients in "vulnerable" groups. *Journal of Medical Ethics* 33(10):591–597.

Buchbinder, M. 2017. Aid-in-dying laws and the physician's duty to inform. *Journal of Medical Ethics* 43(10):666–669.

Buchbinder, M. 2018. Access to aid-in-dying in the United States: Shifting the debate from rights to justice. *American Journal of Public Health* 108(6):e1–e6.

Carlson, B., N. Simopolous, E. R. Goy, A. Jackson, and L. Ganzini. 2005. Oregon hospice chaplains' experiences with patients requesting physician-assisted suicide. *Journal of Palliative Medicine* 8(6):1160–1166.

Colorado Department of Public Health and Education. 2018. *Colorado End-of-Life Options Act, year one: 2017 data summary.* Denver, CO: Department of Public Health and Education Center for Health and Environmental Data.

Dobscha, S. K., R. T. Heintz, N. Press, and L. Ganzini. 2004. Oregon physicians' responses to requests for assisted suicide: A qualitative study. *Journal of Palliative Medicine* 7(3):451–461.

Englander, D. C. 2018. *Report to the Vermont legislature concerning patient choice at the end of life.* Burlington: Vermont Agency of Human Services Department of Health.

Fenn, D. S., and L. Ganzini. 1999a. Attitudes of Oregon psychologists toward physician-assisted suicide and the Oregon Death with Dignity Act. *Professional Psychology, Research and Practice* 30(3):235–244.

Fenn, D. S., and L. Ganzini. 1999b. How do Oregon psychologists view their role in physician-assisted suicide? *Western Journal of Medicine* 171(4):242.

Ganzini, L., D. S. Fenn, M. A. Lee, R. T. Heintz, and J. D. Bloom. 1996. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *American Journal of Psychiatry* 153(11):1469–1475.

Ganzini, L., G. B. Leong, D. S. Fenn, J. A. Silva, and R. Weinstock. 2000a. Evaluation of competence to consent to assisted suicide: Views of forensic psychiatrists. *American Journal of Psychiatry* 157(4):595–600.

Ganzini, L., H. D. Nelson, T. A. Schmidt, D. F. Kraemer, M. A. Delorit, and M. A. Lee. 2000b. Physicians' experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine* 342(8):557–563.

Ganzini, L., H. D. Nelson, M. A. Lee, D. F. Kraemer, T. A. Schmidt, and M. A. Delorit. 2001. Oregon physicians' attitudes about and experiences with end-of-life care since passage of the Oregon Death with Dignity Act. *JAMA* 285(18):2363–2369.

Ganzini, L., T. A. Harvath, A. Jackson, E. R. Goy, L. L. Miller, and M. A. Delorit. 2002. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *New England Journal of Medicine* 347(8):582–588.

Ganzini, L., S. K. Dobscha, R. T. Heintz, and N. Press. 2003. Oregon physicians' perceptions of patients who request assisted suicide and their families. *Journal of Palliative Medicine* 6(3):381–390.

Ganzini, L., E. R. Goy, and S. K. Dobscha. 2009a. Oregonians' reasons for requesting physician aid in dying. *Archives of Internal Medicine* 169(5):489–492.

Ganzini, L., E. R. Goy, S. K. Dobscha, and H. Prigerson. 2009b. Mental health outcomes of family members of Oregonians who request physician aid in dying. *Journal of Pain and Symptom Management* 38(6):807–815.

Gorsuch, N. M. 2006. *The future of assisted suicide and euthanasia*. Princeton, NJ: Princeton University Press.

Harvath, T. A., L. L. Miller, K. A. Smith, L. D. Clark, A. Jackson, and L. Ganzini. 2006. Dilemmas encountered by hospice workers when patients wish to hasten death. *Journal of Hospice and Palliative Nursing* 8(4):200–209.

Hedberg, K., and C. New. 2017. Oregon's Death with Dignity Act: 20 years of experience to inform the debate. *Annals of Internal Medicine* 167(8):579–583.

Miller, L. L., T. A. Harvath, L. Ganzini, E. R. Goy, M. A. Delorit, and A. Jackson. 2004. Attitudes and experiences of Oregon hospice nurses and social workers regarding assisted suicide. *Palliative Medicine* 18(8):685–691.

Oldham, R. L., S. K. Dobscha, E. R. Goy, and L. Ganzini. 2011. Attachment styles of Oregonians who request physician-assisted death. *Palliat Support Care* 9(2):123–128.

Oregon Health Authority. 2018. *Oregon Death with Dignity Act 2017 data summary.* Salem: Oregon Health Authority.

Pearlman, R. A., C. Hsu, H. Starks, A. L. Back, J. R. Gordon, A. J. Bharucha, B. A. Koenig, and M. P. Battin. 2005. Motivations for physician-assisted suicide: Patient and family voices. *Journal of General Internal Medicine* 20(3):234–239.

Smith, K. A., T. A. Harvath, E. R. Goy, and L. Ganzini. 2015. Predictors of pursuit of physician-assisted death. *Journal of Pain and Symptom Management* 49(3):555–561.

Starks, H., R. A. Pearlman, C. Hsu, A. L. Back, J. R. Gordon, and A. J. Bharucha. 2005. Why now? Timing and circumstances of hastened deaths. *Journal of Pain and Symptom Management* 30(3):215–226.

Starks, H., A. L. Back, R. A. Pearlman, B. A. Koenig, C. Hsu, J. R. Gordon, and A. J. Bharucha. 2007. Family member involvement in hastened death. *Death Studies* 31(2):105–130.

# 4

# Experiences with and Reflections on Physician-Assisted Death Internationally

**Key Messages Presented by Individual Speakers/Participants**

- There is an increasing debate in the Netherlands about whether euthanasia or physician-assisted suicide should be available to patients with dementia or psychiatric illness or who have no serious illness but feel that they have completed their lives. (Onwuteaka-Philipsen)
- In the Netherlands, annual reports of the review committees and nationwide studies on euthanasia and other end-of-life decisions held every 5 years are important sources of information for shaping the regulations and for the ongoing public debate. (Onwuteaka-Philipsen)
- Data from the Netherlands show that physicians are reluctant to grant euthanasia requests from psychiatric patients. (Onwuteaka-Philipsen)
- Euthanasia in the Netherlands, which is far more common than self-ingestion of lethal medication, involves a long period of talking and is mostly not about the final day. (Norwood)
- Physician-assisted death laws exist in the context of culture, so caution should be exercised when extrapolating findings from one nation or state to another. (Gibson, Norwood)
- Canadian law attempts to balance a respect for individual autonomy and suffering with protection for the vulnerable. (Gibson)

NOTE: These points were made by the individual speakers/participants identified above. They are not intended to reflect a consensus among workshop participants. The statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

## EUTHANASIA IN THE NETHERLANDS

*Bregje Onwuteaka-Philipsen*
*Professor of End-of-Life Research*
*Vrije University Medical Center*

In the Netherlands, both euthanasia and physician-assisted suicide are legal, although the physician is expected to be present when the patient self-ingests the lethal medication. As Bregje Onwuteaka-Philipsen, a professor of end-of-life research at the Vrije University Medical Center and the Amsterdam Public Health Research Institute, explained, if something goes wrong after self-administration, the physician is then expected to perform euthanasia to complete the process. She also said that in the Netherlands there would be concern about the potential abuse of a prescription if a physician was not present to deliver the lethal medication at the time of death.

The current Dutch law was enacted in 2002, and it requires all physicians who perform either euthanasia or physician-assisted suicide to report each case to one of five regional euthanasia review committees. The review committees comprise a lawyer, a physician, and an ethicist who judge each case on the basis of criteria for due care. If there is a verdict of noncompliance, the case is referred to a public prosecutor who then investigates and makes a decision on whether to prosecute the physician. The criteria for due care include that the physician must

- be satisfied that the patient's request is voluntary and well-considered;
- be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
- have informed the patient about his or her situation and prognosis;
- have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
- have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out above have been fulfilled; and
- have exercised due medical care and attention in terminating the patient's life or assisting in the patient's suicide.

Onwuteaka-Philipsen said that the law is primarily designed to protect the physician. She explained that suffering can be either psychological or physical, which can include a combination of complaints related to old age, and that there is no requirement that the patient be terminally ill. Since the law was enacted, there have been between 80 and 90 cases that were ruled to be noncompliant and referred to the public prosecutor, one of which went to trial.

There are several sources of information on the practice of euthanasia and physician-assisted suicide in the Netherlands. Annual reports from the five review committees include characteristics of all the reported cases. However, Onwuteaka-Philipsen said, these are limited to cases reported to the review committees, making it impossible to investigate instances of non-reporting. Furthermore, the annual reporting does not contain information on who has requested but been denied euthanasia or physician-assisted suicide. The report also lacks case details that would provide context for the end-of-life decision-making process. Onwuteaka-Philipsen said that the Dutch government has commissioned a nationwide evaluation study every 5 years since 1990, the first three of which led to changes in the regulation procedure and eventually to the Dutch law in 2002 regarding euthanasia. These studies consist of a death certificate analysis in which a questionnaire is sent to the attending physician of a stratified sample of deaths as well as a survey among a stratified sample of physicians in order to study trends in end-of-life decisions. Furthermore, specific topics are addressed with qualitative methods.

An analysis of 25 years of data on all deaths in the Netherlands found that the incidence of euthanasia rose significantly between 2010 and 2015, while physician-assisted suicide has remained low and the incidence of the illegal practice of ending life without an explicit request has fallen (van der Heide et al., 2017) (see Figure 4-1). Onwuteaka-Philipsen said that combining the results of this study with the number of reported cases of euthanasia and physician-assisted suicide shows that the notification rate has increased since the enactment of the 2002 law (see Figure 4-2).

Onwuteaka-Philipsen said that the percentage of deaths preceded by a request for euthanasia or physician-assisted suicide rose from 5.2 percent in 2005 to 8.4 percent in 2015 (van der Heide et al., 2017). At the same time, the percentage of requests that were granted also rose, from 39 percent in 2005 to 55 percent in 2015. It continues to be the case that most patients requesting either procedure have cancer or a serious somatic disease, she said, but the incidence of euthanasia has increased somewhat in older people (see Figure 4-3). Onwuteaka-Philipsen said that there is a growing debate in the Netherlands about whether euthanasia or physician-assisted suicide should be available to patients with dementia or psychiatric illness or who have no serious illness but feel that they

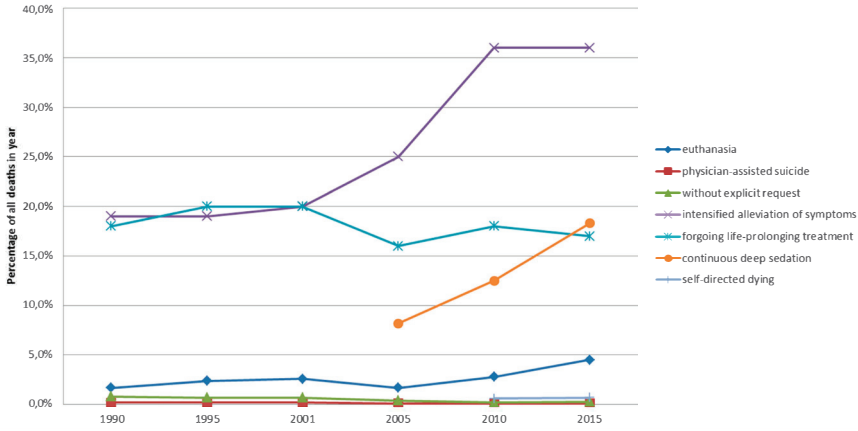


**FIGURE 4-1** Frequency of euthanasia, physician-assisted suicide, and other end-of-life decisions in the Netherlands.
SOURCES: Onwuteaka-Philipsen presentation, February 13, 2018. Data from van der Heide et al., 2017.

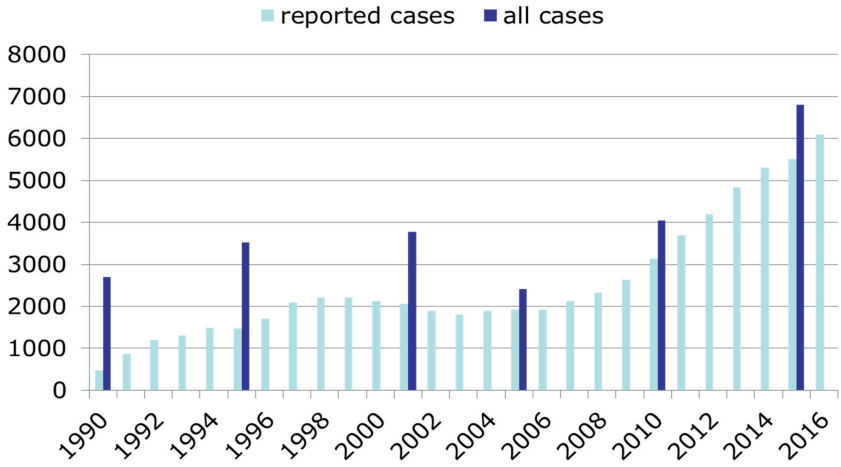


**FIGURE 4-2** Number of cases of euthanasia and physician-assisted suicide, reported and total, in the Netherlands.
SOURCES: Onwuteaka-Philipsen presentation, February 13, 2018. Data from Onwuteaka-Philipsen et al., 2017.

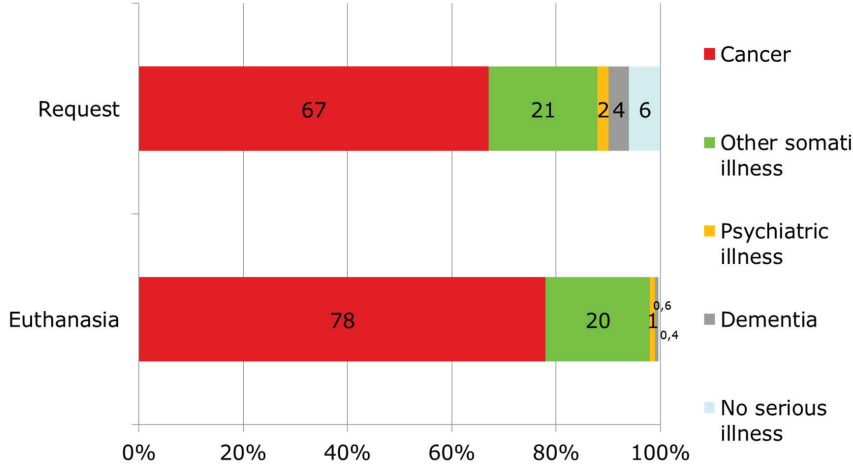


**FIGURE 4-3** Source of suffering in explicit euthanasia requests and euthanasia cases in 2016 in the Netherlands.
SOURCE: Onwuteaka-Philipsen presentation, February 13, 2018.

have completed their lives. To illustrate the types of information gathered in the Dutch process, she used the example of psychiatric illness. The absolute number of reported cases of patients with a psychiatric diagnosis completing either process has risen substantially over the past few years—from 13 in 2011 to 60 in 2016—but as a percentage of all cases, the numbers remain low (there were 6,091 reported cases in 2016) (Regional Euthanasia Review Committees, 2017). Surveys of psychiatrists in 1995, 2008, and 2016 found that there was an increasing number of requests from patients with a psychiatric diagnosis, though in all years most of those requests were refused (see Figure 4-4). The main reason that psychiatrists rejected 94 percent of these requests was because they did not meet the due care criteria.

Furthermore, Onwuteaka-Philipsen said, a survey of the Dutch public and Dutch physicians revealed how reluctant physicians are to grant a request for euthanasia or physician-assisted suicide for a patient with a psychiatric diagnosis. While 80 percent of the physicians said it was conceivable they would grant such a request from a cancer patient, only 37 percent said it was conceivable to ever grant a request from a psychiatric patient. In contrast, 53 percent of the public said euthanasia and physician-assisted suicide should be allowed for a patient with a psychiatric diagnosis, compared with 88 percent who said it should be allowed for cancer patients (Onwuteaka-Philipsen et al., 2017).

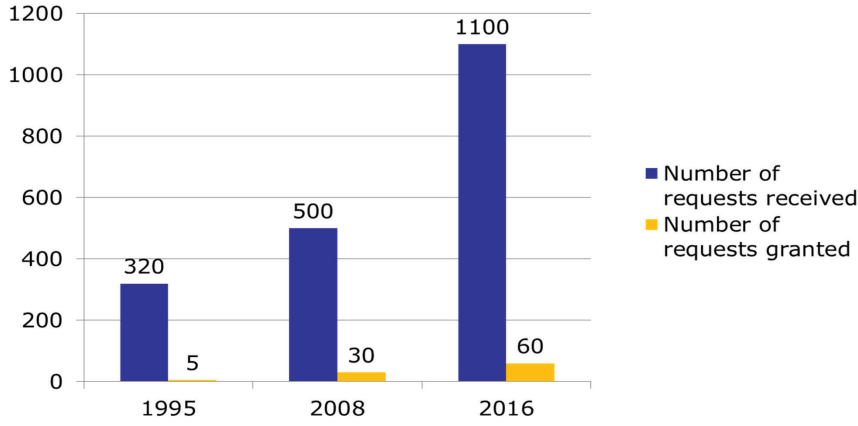


**FIGURE 4-4** Estimates of requests and granted requests from psychiatric patients in the Netherlands.
SOURCE: Onwuteaka-Philipsen presentation, February 13, 2018.

*Frances Norwood*
*Assistant Research Professor of Anthropology*
*George Washington University*

When Frances Norwood, an assistant research professor of anthropology at George Washington University, began studying euthanasia and end-of-life care, she went to the Netherlands. Norwood explained that what she discovered through her research in the Netherlands was not what she expected. The purpose of her study was to set aside the law, opinion studies, and the hypothetical and to go into people's homes and find out what euthanasia really looks like in practice. She said she anticipated studying death and dying but what she found was actually something quite different.

Her study focused specifically on euthanasia, which is more widely used than physician-assisted suicide in the Netherlands. According to Norwood, Dutch doctors and families find physician-assisted suicide unpredictable, so they tend not to pursue it. Norwood spent 15 months between 1999 and 2001 in Amsterdam and in a cluster of small towns outside of the city sitting with people who were dying. Each day, she would sit in the office with a different general practice physician and go on house calls to see the more seriously ill and end-of-life patients. She returned to the Netherlands in 2008 and did follow-up interviews with some of the same family members and doctors.

Before discussing her findings, Norwood told the story of one patient,

an 80-year-old woman with terminal breast cancer that had spread to her lymph nodes. Over time, her symptoms worsened, and she was unable to eat with her husband or get outside in her garden, two things that were very important to her. When she requested euthanasia from her doctor, the doctor was shocked, as this woman felt like a grandmother to her. Nevertheless, she did what all of the doctors that Norwood met with in the Netherlands do, which was to schedule family meetings to discuss the euthanasia request. These meetings typically involved going from family member to family member and talking about how they feel about the request. Over the last 3 weeks of this woman's life, her doctor visited almost daily, talking with her and listening to her life story. On her final day, in her hospital bed on the first floor of her own home, she said goodbye to her husband, son, and neighbors and died peacefully.

What this story illustrates, Norwood said, is that euthanasia in the Netherlands involves discussions taking place over weeks, months, and sometimes years and does not largely focus on the final day itself. A caveat to this conclusion, she noted, is that she was working with general practitioners and not specialists, so the patients tended not to be the sickest and thus had time to process their illnesses. As a result of this long discussion process, few patients actually followed through on their request for euthanasia, she said. The three main reasons she found for people not ultimately choosing euthanasia were that a family member was not ready, the person changed his or her mind over time, or the patient never restarted the process after the physician stalled on the initial request for assisted death.

In practice, Norwood said, patients get activated by the process and begin talking about what matters most to them. At the same time, physicians get more involved with the patient because now they have something to do in the wake of a terminal prognosis. Families become more involved, too, and social bonds are better maintained at a time when they are often slipping. In Norwood's experience, she said, people typically did not go through with euthanasia because they received the satisfaction and contentment they needed through the dialogue occurring between themselves, their loved ones, and their physicians. In essence, talking euthanasia became a palliative practice, solidifying social bonds near the end of life and making a euthanasia death unnecessary for some.

Laws exist in the context of culture, Norwood noted, so she cautioned against extrapolating these findings to how physician-assisted death occurs in Oregon or any jurisdiction where it is legal. She explained that the ways in which Montana, Oregon, and Washington, DC, might practice physician-assisted death are all going to be slightly different. The practice of physician-assisted death is going to be based on cultural processes and cultural ways of thinking, feeling, acting, and understand-

ing, she said. She emphasized that the important question to ask regarding physician aid-in-dying is whether it is something that fits within U.S. culture. Norwood closed with a request to consider the cultural context and said that this is a practice that goes beyond what is written in law.

During the discussion period, Daniel Sulmasy of Georgetown University asked Norwood whether there is a connection between a request for assisted suicide or euthanasia and the meaningful family meetings, doctor visits, and opportunities for reconciliation. That is, Sulmasy said, why should it be that a patient only gets the opportunity for discussions with family and the possibility of reconciliation that Norwood mentioned if they ask for euthanasia? Norwood replied that Dutch practitioners generally are very involved with the families of patients from the beginning, but once a request for euthanasia is made, it gives practitioners more power to initiate difficult discussions.

## THE CANADIAN EXPERIENCE

*Jennifer Gibson*
*Sun Life Financial Chair in Bioethics*
*University of Toronto*

Jennifer Gibson, the Sun Life Financial Chair in Bioethics and the director of the University of Toronto Joint Centre for Bioethics, agreed with Norwood on the importance of cultural and historical context. She told the audience that the context surrounding physician aid-in-dying in Canada will be different than the context in the Netherlands or in the United States. The Canadian story starts in 1993, when a woman in her early 40s with amyotrophic lateral sclerosis (ALS) sought an amendment to the criminal code so that her physician could help her die. At the time, the Supreme Court of Canada ruled 5-4 against physician-assisted death. Then, in 2015, the Supreme Court of Canada ruled 9-0 in favor of changing the criminal code to allow assisted death. As a result of this ruling, Canada enacted Bill C14, An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), in June 2016. Thus, Gibson said, physician aid-in-dying was part of Canadian conversation and consciousness for 22 years before a law concerning it was formalized.

What changed over time was public perspectives on the issue, Gibson said. In recent years a number of opinion polls have been conducted, and a convergence of public opinion emerged with 75 percent of Canadians supporting legalization of medically assisted death in Canada. One factor that drove the change in public attitude was the experience drawn from Oregon and the Benelux countries (Belgium, Luxemburg, and the

Netherlands), and the court noted this experience in making its ruling. Also influencing that decision was the Province of Quebec's passing of integrated legislation related to end-of-life care which introduced the right to palliative care and the right to what the provincial legislation called medical aid-in-dying. Quebec's legislation resulted from 5 years of consultation with residents and an iterative process to craft the law. The final factor, Gibson said, was that there were some shifts in clinical perspectives. In surveys conducted by the Canadian Medical Association, members supported legislation on medical aid-in-dying, but there was some reticence among those surveyed about being a provider of the practice.

One important factor in the Canadian context, said Gibson, is that criminal code amendments come under federal jurisdictions, but health care is primarily a provincial and territorial matter. This, Gibson said, created an interesting legal conundrum about the proper division of power. If Canada were to introduce legislation at the federal level, it would need to be translated in some way into the provincial and territorial practices in a coherent way, she explained. The diversity in the way that the Canadian provinces and territories organize their health systems means there is some heterogeneity in terms of how they provide medical aid-in-dying to residents.

Gibson said that geography is another key factor in the Canadian context. In the northern territories, for example, nurse practitioners are the primary caregivers, rather than physicians. Because of such differences, Gibson said, geographic diversity and diversity in jurisdictions will need to be considered by anyone who is serious about implementing medical aid-in-dying in Canada.

In Canada, the new law provides protections for both physicians and nurse practitioners whose scope of practice includes medication prescribing and administration. The law permits both clinician- and self-administration for a person over age 18 who is capable of making his or her own decisions related to health and who is legally eligible for health care in Canada. In addition, the individual must have a "grievous and irremediable" medical condition, must make a voluntary request that is not the result of external pressure, and must be informed of all available alternative options for his or her care.

Gibson said that the requirement of a "grievous and irremediable" medical condition has been a challenge for clinicians to interpret. In Canada, it has been interpreted as saying that the patient must have a condition that is serious or incurable and be in an advanced state or in irreversible decline. In addition, the individual must be experiencing enduring physical or psychological suffering that is intolerable and that cannot be addressed by means acceptable to the individual and

that the individual's natural death is reasonably foreseeable under these circumstances.

The Canadian law also lays out a number of procedural requirements, including requirements related to the nature of the request, how the request is conducted, how it is signed, and how it is witnessed, while recognizing that not everyone can make a written request. The law requires two independent practitioners to confirm eligibility and 10 days between the request and the provision of the medication. The law allows for the 10-day waiting period to be shortened in the case of imminent death or imminent loss of competence. Gibson said that in his opinion, the Canadian law attempts to balance a respect for individual autonomy and suffering with protection for the vulnerable.

Since the law was passed, less than 1 percent of Canadian deaths have resulted from medically assisted death, with more than 99 percent of those deaths being clinician administered. The individuals who have taken advantage of the law have ranged in age from 18 to 102, with the average age being 73 and the majority over the age of 55. Approximately 60 percent of the patients had a cancer diagnosis, and another 18 percent had neurodegenerative disorders. About 50 percent of the deaths occurred in hospitals in large urban areas, Gibson said, though a movement is starting in favor of having deaths in private residences, hospices, or long-term care facilities.

## REFERENCES

Onwuteaka-Philipsen, B. D. L., A. van der Heide, H. J. van Delden, K. Evenblij, I. El Hammoud, H. R. W. Pasman, C. Ploem, R. Pronk, S. van de Vathorst, and D. Willems. 2017. *Third evaluation of the euthanasia law*. ZonMw. The Hague, the Netherlands. [In Dutch].

Regional Euthanasia Review Committees. 2017. *Regional euthanasia review committees annual report 2016.* The Hague: Regional Euthanasia Review Committees. https://www.eutanasia.ws/_documentos/dossier_eutanasia/PaisesBajos_Balegica/17%20Netherland%20Annual%20Report%202016.pdf (accessed May 24, 2018).

van der Heide, A., J. J. M. van Delden, and B. D. Onwuteaka-Philipsen. 2017. End-of-life decisions in the Netherlands over 25 years. *New England Journal of Medicine* 377(5):492–494.

# 5

# Implementation and Practice of Physician-Assisted Death

**Key Messages Presented by Individual Speakers/Participants**

- One issue with all current regulations and laws on physician-assisted death is that they do not specify an implementation process, that is, what happens from the time the prescription is written until the patient's death. However, these laws do not preclude providers from establishing their own procedures and best practices. (Campbell)
- Physician-assisted death is no longer an anomaly, and it is changing the experience of dying for everybody—not just the people who decide to use it. (Back)
- The primary value of Oregon's law is the high level of open communication it creates among physicians, patients, and families surrounding the end of life. (Reagan)
- Health professionals should never suggest physician aid-in-dying as an alternative to care. (Fromme)
- Based on currently available data, safeguards may be largely too restrictive in U.S. states where the practice of physician-assisted death is legal. (Pope)
- Institutional responses to the newly legalized physician aid-in-dying option in California have been challenging to design and implement, and these responses require significant resources, including clearly identified patient navigators. (Koenig)

- Challenges exist to capturing information about how end-of-life practices are affecting patients from diverse backgrounds. Best practices are needed for collecting data about physician aid-in-dying to allow researchers to study the impact of the law on various populations. (Koenig)
- Palliative care teams can be fully participatory and serve as primary contacts in an institutional approach for physician-assisted death. (Harman)
- Assisted dying is a low-frequency, high-risk medical procedure, and, as such, the medical profession should stop waiting for government to decide how to manage it. (Wynia)
- There is no state-collected information on who is writing prescriptions for lethal medications, about how many patients had to change doctors to access this service, or about the concerns and motivations of patients for seeking physician-assisted death. (Wynia)
- There is a need for data not just on physician-assisted death but on all aspects of end-of-life care. (Hedberg)
- The research community, not just government, needs to be involved in data collection efforts. (Gibson)

NOTE: These points were made by the individual speakers/participants identified above. They are not intended to reflect a consensus among workshop participants. The statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

## SAFEGUARDS

*Thaddeus Pope*
*Director, Health Law Institute*
*Mitchell Hamline School of Law*

At the time of the workshop, five states (California, Colorado, Oregon, Vermont, and Washington) and the District of Columbia had approved medical aid-in-dying laws,[1] and more than half of the remaining states had

[1] A 2009 Montana Supreme Court decision ruled that state law protects Montana physicians from prosecution for helping terminally ill patients die. See *Baxter v. Montana*, 224 P.3d 1211 (2009). This information was added after prepublication release. Therefore, no legislation exists in Montana to serve as the basis for a discussion of safeguards in that state. In addition, Hawaii legalized physician-assisted death in April 2018, after this workshop took place.

bills under consideration to affirmatively legalize medical aid-in-dying, said Thaddeus Pope, the director of the Health Law Institute and a professor of law at the Mitchell Hamline School of Law. Existing and proposed statutes include the same safeguard provisions included in the initial Oregon law. The safeguards are (1) a mental health evaluation to evaluate impaired judgment, (2) terminal illness, (3) self-administration, (4) limitation to adults, (5) capacity (i.e., no advance directives), (6) waiting period, and (7) certification by two physicians (i.e., no nurse practitioners). Pope addressed the issue of whether these seven safeguards are too weak or too strong based on the available data. He stressed that he was not making an argument pro or con, but rather an objective presentation of how institutions and legislatures are approaching safeguards surrounding medical aid-in-dying.

In terms of the current safeguards being potentially too weak, Pope said he only had one good example, and that involves the mental health evaluation for determining impaired judgment. The problem with that, he explained, rests with how individuals are screened for impaired judgment resulting from a mental disorder. While the current and proposed laws all call for physicians to refer individuals to a mental health specialist if they suspect there is a mental health issue, that referral happens rarely (Oregon Health Authority, 2018). Less than 5 percent of the patients who received prescriptions through medical aid-in-dying laws were referred for a mental health screening (Oregon Health Authority, 2018), and that number has been decreasing over time.

Many of those who argue against medical aid-in-dying believe that this referral rate is too low. In response, Pope said, some institutions now require a mental health screening for everyone who seeks to receive a prescription for lethal medication, and some jurisdictions have sought to include mandatory screening in their laws. Scotland included mandatory screening in its proposed law, which did not pass, and Belgian law includes mandatory screening for some categories, such as for individuals who are not terminally ill and for mature minors (Boring, 2014; Scottish Parliament, 2010). Pope said that he knew of no evidence to suggest that individuals with impaired judgment were accessing lethal prescriptions when they should not have been able to do so under the law, but it is an area worthy of additional research.

Are the safeguards too strong? Pope said that there are six examples that suggest the eligibility requirements for access to physician-assisted death may indeed be too stringent. The first example is the requirement that a patient have a terminal and irreversible illness that will cause death within 6 months. There are many people who, at least in their own judgment and estimation, are suffering unbearably but are not terminally ill, he said, and such individuals would be excluded from access in the

United States in the absence of a terminal illness. Even the American College of Physicians, which is opposed to what it calls "physician-assisted suicide," admits that it is arbitrary to limit the option to people who are terminally ill (Snyder Sulmasy and Mueller, 2017).

Victoria, Australia, recently passed a medical aid-in-dying law that extends the time frame for prognosis to 12 months for neurodegenerative disorders such as amyotrophic lateral sclerosis (ALS). The premier of Victoria noted in a tweet that this law is the most conservative, voluntary assisted dying model ever proposed or implemented in the world.[2] On the other hand, Pope said, Canada has dropped an exact time limit and instead requires that death be "reasonably predictable." There is no time limit on access in laws governing assisted death in Belgium, Luxembourg, or the Netherlands.

Another area where the current U.S. state laws may be too strict, said Pope, is their requirement for self-administration of the lethal medication. This requirement is designed to help assure voluntariness, Pope explained, but some individuals lose the ability to self-ingest the medication. In addition, some people have complications from self-ingestion, as shown by the 3 to 6 percent complication rate noted in the latest data from Oregon (Oregon Health Authority, 2018). Pope added that the complication rate may rise as the practice moves away from using secobarbital to newer medications that do not have the same track record (Oregon Health Authority, 2018). Belgium, Canada, Luxembourg, and the Netherlands avoid this potential problem by allowing clinicians to administer lethal medications. Victoria's new law allows physician administration, but only in the case where a patient is physically incapable of self-administration or digestion.

The third safeguard Pope discussed was the requirement that access to physician-assisted death be limited to adults, which is designed to assure that the decision is voluntary and informed. However, many U.S. states allow minors to make other life-and-death health care decisions about life-sustaining treatment. Canada, which currently restricts medical aid-in-dying to adults, is considering whether to extend the law to mature minors (Gerein, 2017). Current laws in Belgium and the Netherlands allow minors to access assisted death.

Pope then considered the safeguard concerning capacity that requires the request be made directly by the individual and not by advance directive. The problem here, he said, is that by the time someone with dementia is terminally ill, that person will not have the capacity to request the procedure. He noted that the Alaska state Supreme Court said it would

[2] Tweet from @DanielAndrewsMP on November 21, 2017, https://twitter.com/danielandrewsmp/status/933201795106594816?lang=en (accessed March 25, 2018).

be unconstitutional to allow medical aid-in-dying contemporaneously, but to not allow it by advanced decision.[3] Belgium, Luxembourg, and the Netherlands allow consent by advance directive, and Canada is currently considering this expansion as well.

The fifth provision that may be too strict, according to Pope, is the requirement that multiple requests for the lethal medication be separated by a specified waiting period. This requirement seems to be a good idea in that it ensures that the request is enduring, settled, and deliberative, but many, Pope said, have written that it imposes an undue burden on some patients (Ouellette, 2017). Victoria addresses this problem in its new law by allowing the waiting period to be waived if there is a certification that the death is likely to occur before the expiration of the waiting period.

The final requirement Pope considered was the provision that requires certification by both an attending and a consulting physician who must each be an M.D. or a D.O. licensed in the state. This requirement can cause a serious access problem when it comes to finding two available and willing physicians, Pope said, adding that there is a growing literature on whether nurse practitioners should be included in the list of eligible providers, just as they are now with physician order for life-sustaining treatment forms (Stokes, 2017). Canada allows nurse practitioners to sign the certification form for requests for assisted death, and several states are considering bills to allow that as well.

## ACCESS

*Courtney Campbell*
*Hundere Professor of Religion and Culture*
*Oregon State University*

Regarding access, Courtney Campbell, the Hundere Professor of Religion and Culture at Oregon State University, said that another issue has become the cost of the lethal medication. The preferred medication, secobarbital, now costs approximately $3,000–$5,000 for a lethal dose (Death with Dignity National Center, n.d.). Other less expensive drug combinations have been introduced, but these have some additional side effects. Another access-related issue arises from the complexity of the bureaucratic process that a patient must go through to receive a prescription under the current laws (see Figure 5-1), which Campbell said is difficult for both patient and physician to navigate.

Campbell said that most of the issues Pope discussed are being looked at in other countries and that they are not new issues. "They were pres-

[3] *Sampson v. Alaska*, 31 P.3d 88. (2001).

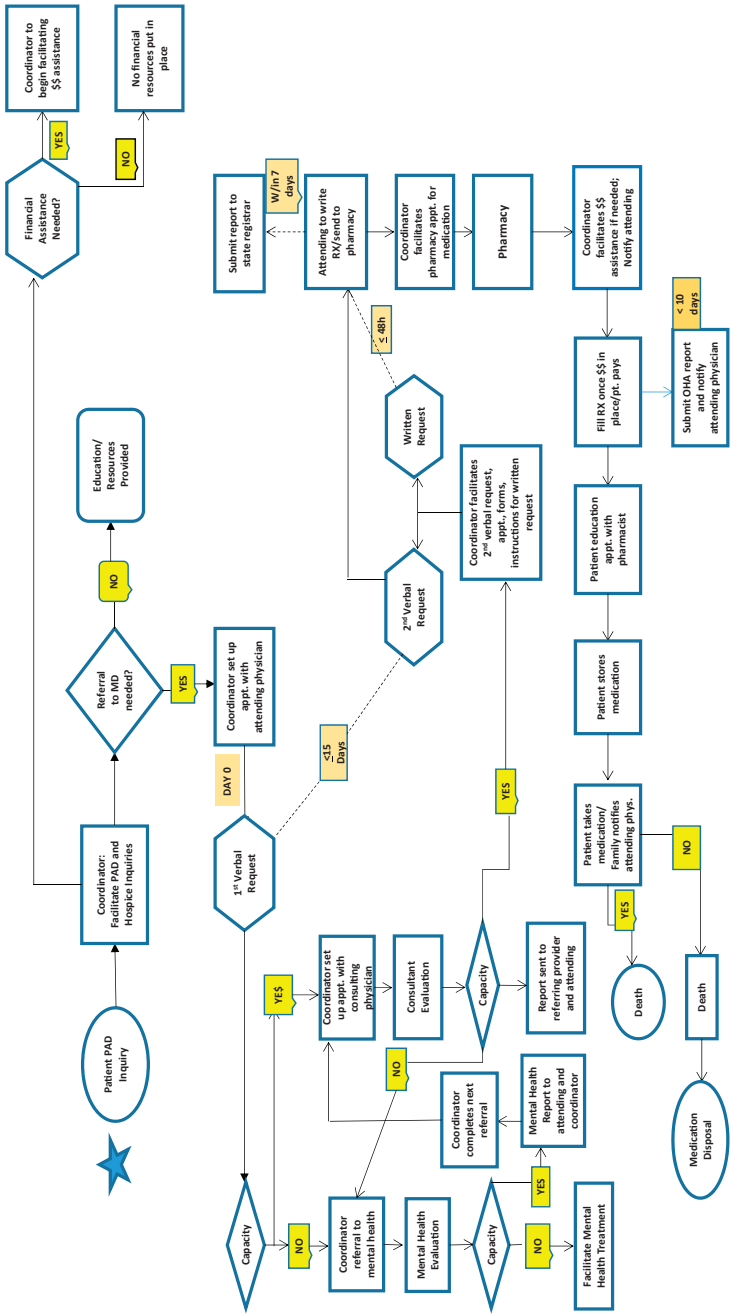


**FIGURE 5-1** Potential patient navigator system for physician-assisted death.
NOTE: MD = medical doctor; PAD = physician-assisted death; RX = prescription.
SOURCE: Campbell presentation, February 12, 2018. Created through collaboration with Thomas Steele, M.D.

ent in the Oregon discussion of 1993 to 1994," he said. Campbell pointed out that in 2017, the Oregon legislature considered, but did not pass, an amendment to the current law that would have allowed a patient who had executed a lawful advance directive to identify an agent, called an attorney-in-fact, who could collect and administer the lethal medication if the patient had already received the prescription but had not yet received the medication.[4] Campbell suggested it is worthwhile to consider why that kind of proposed advance directive process was debated and refused in 1993, 1994, and 2017.

In his opinion, he said, if the discussion about safeguards were to be focused primarily on the best interest of patients, rather than those of physicians and pharmacists, the answers to these questions might be different. Safeguards are built into the laws to ensure that physicians or pharmacists would be immune from prosecution, Campbell explained. This way, he said, physicians and pharmacists do not have to make quality-of-life assessments about extraordinary suffering or directly administer a lethal agent into the patient's body, but simply are responsible for determinations of capacity. Similarly, because the Oregon law imposes no legal duty on any health care professional to participate in prescribing lethal medication, the provision acts as a safeguard against involuntary participation by physicians or pharmacists, who can choose to participate or not with moral integrity. Campbell indicated that the safeguards were also written into the laws to assure the public that the process would not be abused and to prevent the unregulated incidents that had received so much publicity as a result of Jack Kevorkian's activities.

One problem with the current regulations in Oregon, Campbell said, is that they do not specify an implementation procedure, that is, what happens from the time the prescription is written until the patient's death. According to Campbell, there is some level of unknown in at least 50 percent of the Oregon deaths that are reported (Hedberg and New, 2017). The unknowns include whether there was a provider present at the time of medication ingestion, the duration between ingestion and unconsciousness, and the duration between ingestion and death.

However, the law does not preclude providers in different environments, such as the hospice setting, from developing best practices to help address some of these concerns. For example, between 75 and 90 percent of the patients who use physician-assisted death in California, Colorado, Oregon, and Washington (the percentage varies by state) are enrolled in hospice (California Department of Public Health, 2017; Colorado Department of Public Health and Education, 2018; Oregon Health Authority,

[4] 79th Oregon Legislative Assembly, SB 893, "A Bill for an Act" to amend ORS 127.800, 2017.

2018; Washington State Department of Health, 2017). Campbell explained that hospice becomes an important safeguard for many of the issues that might cause concern if there is a one-on-one relationship between the physician and patient. Hospice care is based on a team philosophy, and hospice best practices could ensure that patient requests for physician-assisted death are voluntary, informed, and not motivated by uncontrolled pain or financial concerns.

## PHYSICIAN PERSPECTIVES

*Anthony Back*
*Professor of Medicine*
*University of Washington*

Anthony Back told the workshop that from his perspective as a medical oncologist and palliative care physician, thinking about physician-assisted dying is no longer just for social pioneers. Back is a professor of medicine at the University of Washington and a co-director of the university's Cambia Palliative Care Center of Excellence. Early on, Back said, he located an advocacy organization, End of Life Washington, that provides "end of life counseling to . . . qualified patients who desire a peaceful death," among other services, including promoting the use of physician order for life-sustaining treatment forms.[5] However, Back said, nowhere on that organization's website does it recommend that patients find a palliative care doctor before pursuing physician-assisted death.

Back noted how Google searches of various words associated with end of life reveal some interesting patterns (see Figure 5-2). Searches on the word "hospice" far outnumber those on "euthanasia," "end-of-life care," "palliative care," and "assisted suicide," but those on "euthanasia" exceed those of "palliative care" and "end-of-life care." Back concluded, "If you are an American looking at what happens in Google searches, you would conclude that a lot more people are searching for euthanasia than they are searching for palliative care." A similar pattern is evident in worldwide searches, he added.

Back said he wonders if the public's current confusion about the different options available for end-of-life care, as indicated by the Google search histories in Figure 5-2, represents an erosion of confidence in the medical care system or if there really is a new segment of the population that is willing to think about death in different ways. He said that colleagues of his at the University of Washington put an advance directive

[5] For more information, see https://endoflifewa.org (accessed April 30, 2018).

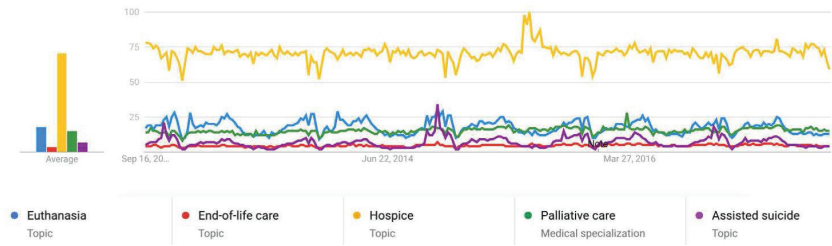


**FIGURE 5-2** Google searches in the United States related to the end of life, 2012–2017.
SOURCES: Back presentation, February 12, 2018. Data from Back's personal communication based on Google Trends analysis 2017.

for dementia on the Web and it was downloaded 43,000 times after it was mentioned in *The New York Times* (Gaster et al., 2017; Span, 2018).

Another aspect of physician-assisted death that Back said he considers to be important is the increasing number of patients he sees who want to access it because they want to have the option in the future, not because they have intolerable suffering in the present moment. Back said that he sees something of a "gift exchange" between patients who consider physician-assisted death and their loved ones—that is, the patient gives his or her loved ones a new perspective on approaching death, while receiving the gift of a "good" death in return. Back clarified that this concept of a "gift exchange" is complicated and not well described or understood and therefore an area for further research. As an example, he noted *The New York Times* story about John Shields, a social activist in British Columbia who used the new Canadian law and held his own Irish wake in the inpatient hospice ward where he was living a couple of days before he died (Porter, 2017). People showed up to this party who had not previously wanted to talk to him, and others used this occasion to make a final connection with him. This is not a new phenomenon, Back said, as there are records of the practice in ancient times, and goodbye parties became common in the time of HIV/AIDS (Mullan, 2000).

While the circumstances surrounding physician-assisted death are not quite analogous, Back said he thinks that there is something important about the idea of making arrangements so that the individual has the opportunity to better control various factors around their own death. He also sees this as a way for loved ones to say goodbye and perhaps make the grieving process easier for them.

Back also said that physicians and the public are experiencing a learning curve with the practice of physician-assisted death. In the first 6

months that California's law was in effect, physicians who chose to prescribe lethal medications overwhelmingly did so for just one requesting patient. The first year that Oregon's law went into effect told a similar story, with 14 physicians writing prescriptions for 15 patients (Chin et al., 1999). In the initial period after assisted-death legislation is passed, physicians individually have experience with a small number of cases. With physicians experiencing and responding to such a high-stakes procedure, it raises concerns about quality if a physician has no experience helping patients through the process. Back also mentioned the importance of physicians getting the appropriate support and training to have the sometimes subtle conversations about end of life. He said that End of Life Washington has a group of counselors, psychologists, and physicians who have been working together for 20 years doing this kind of counseling. This is a very intensive system, he said, and he wondered how to scale that type of program in California, which is 10 times the population of Washington. Back said that while physicians may be willing to participate, they will still need to have some training, both for their benefit and the benefit of patients.

To help patients navigate through the decision-making and documentation process, Back and colleagues at his institution have developed a death-with-dignity program (Loggers et al., 2013) based on a similar program implemented at Oregon Health & Science University. He has also worked with a large health system in California to teach its physicians that physician-assisted death is not about the law, but rather about the patient's goals for end-of-life care. This health care organization, he said, has built a system of peer mentoring to support physicians. The effect of participating in an assisted death must be evaluated for clinicians just as it is for others who are part of the process, Back said, as he has observed a small number of negative psychological outcomes for clinicians who participate in assisted deaths. In closing, Back said that physician-assisted death is no longer an anomaly, and it is changing the experience of dying for everybody—not just the people who decide to use it.

### *Peter Reagan*
### *Retired Family Physician, Oregon*

Peter Reagan is a retired family physician who practiced for more than 30 years in Portland, Oregon. In March 1998, under Oregon's new medical aid-in-dying law, he wrote the first legal prescription in the United States for a lethal medication. Over the next 13 years, he wrote some 25 prescriptions, of which 15 were used for a planned death. Reagan said he was present for three of these deaths, including the first. After he retired

from medical practice, for a few years he advised doctors in Oregon on the use of the law.

Reagan said that as he sees it, Oregon's experience of the past 20 years has allowed the debate to move from whether aid-in-dying should be legal to how to best address the desire for it. He said he supports Oregon's law, particularly because of the enhanced potential for communication it creates with patients and families. He noted that after 20 years and some 1,500 cases of aid-in-dying in Oregon, there has not been a single complaint of misuse filed with the Oregon medical board and almost no unexpected complications (Oregon Health Authority, 2018).

Reagan said that while there has been a fair amount written about a number of issues surrounding aid-in-dying, there has been little discussion in the literature about the communication that takes place among patients, family members, friends, caregivers, hospice workers, and other physicians when a request for aid-in-dying is made. Reagan stressed that physicians should look for consistency of requests for aid-in-dying from patients over time. Reflecting on the psychological and emotional burden for physicians, Reagan said that the more time a physician spends with the patient and his or her trusted circle of family and friends, the more comfortable the physicians can feel with an eventual decision to assist in a patient's death.

Reagan recalled how before writing his first prescription, he spoke at length with the patient, each of her two adult children, both of her previous physicians who had been unwilling to consider prescribing, two hospice nurses, the hospice social worker, and the consulting physician as well as making a visit to the patient's home to discuss the matter in a family setting. Talking to the patient's usual physician, even if that physician will not provide the prescription, can provide valuable perspective on whether the patient would qualify under the law. He stressed the importance of avoiding prescribing the lethal medication if there is any real disagreement about whether the patient qualifies. Reagan also expressed his belief that the primary value of Oregon's law is the high level of open communication it creates and requires among physicians, patients, and families. He said that communication is the essence of why an aided death feels so unlike death by suicide.

For patients who are not qualified under the law, Reagan said he favors alternatives such as palliative sedation or voluntarily stopping eating and drinking (VSED), as opposed to any illegal or clandestine approach, as these alternatives allow for a better resolution of unfinished business with loved ones.

Reagan said that there are specific illness-related issues that can affect how well a patient can self-administer and ingest life-ending medication. Patients with ALS, for example, can be mentally competent and yet have a

great deal of difficulty self-administering oral medications. Some patients have complied with the self-administration requirement by finding or inventing a way to initiate the flow of medication into a feeding tube. A difficult situation, Reagan said, is with people who have a poorly functioning digestive system, particularly when there is frequent vomiting, as these individuals are unable to absorb oral drugs and therefore cannot use the law. Another sad circumstance, he said, involves progressive dementing illness in which the patient loses decisional capability long before he or she is terminally ill. No state's laws address this situation, leaving voluntarily stopping eating and drinking as the only legal choice for hastening death in this setting in the United States.

After ingestion of a lethal medication, unconsciousness occurs usually within minutes, and death results within an hour. However, a prolonged dying process is more common than many believe, Reagan said. Early data collected in Oregon suggested that about 15 percent of patients were still alive after 8 hours, and 1 to 2 percent lived more than 24 hours. An even smaller number, perhaps 1 in 200, might reawaken (Oregon Health Authority, 2018). This type of outcome is more common in patients with gastrointestinal cancer, when unusual prescriptions are used, when there is vomiting, or when a patient eats a large meal before ingesting the medication, he said.

According to Reagan, about 20 percent of oral aid-in-dying patients in the Netherlands received some form of intravenous euthanasia 2 or so hours after ingestion.[6] In Oregon, when a dying process goes on for more than 8 to 12 hours, or when vital signs appear to be strengthening, buccal morphine or topical fentanyl patches are sometimes used. Reagan spoke of the value of discussing a prolonged dying process with the patient and family in advance, and he questioned whether legally, intentionally, and publicly ingesting a lethal prescription constitutes a form of consent for palliative sedation if that lethal medication fails to work as intended.

Perhaps the most frustrating aspect of aid-in-dying for patients and families is the lack of care continuity that results when the patient's usual physician or health care system opts out of the program, Reagan said. In his opinion, he said, the current legal process is not too onerous when the usual primary care physician and relevant specialists are supportive. Under these circumstances, he said, the time from first request to prescription can easily be close to 3 weeks. However, it can take closer to 2 months when the first request requires finding a new doctor.

Reagan identified two modifications to current laws that could improve access without compromising safeguards. One such modification

[6] Calculated from the Netherlands Regional Euthanasia Review Committee's Annual Reports, 2002–2016.

would be to shorten the waiting period between requests. Instead of 15 days, 7 days should be possible, given research showing that even 3 days of attitudinal consistency correlates with long-term reliability (Chambaere et al., 2015; Lewis and Black, 2012; Oliver, 2016; Onwuteaka-Philipsen et al., 2010). It would be appropriate, he added, for a provider to require a longer waiting period in any circumstance where the decision appears to be unclear. Another issue is interstate reciprocity. It can be common for a patient to live in Washington State but work and get medical care in Portland, Oregon. Currently, a patient requesting assisted death would need to have all of the medical records based on his or her state of residence in order to access the law.

*Erik Fromme*
*Director, Serious Illness Care Program, Ariadne Labs*
*Dana-Farber Cancer Institute*

Erik Fromme, the director of the Serious Illness Care Program at Ariadne Labs, recently left a position as the director of palliative care at Oregon Health & Science University, where for 15 years he chose not to prescribe lethal medications for patients requesting physician-assisted death. As a non-prescriber, he had experience working with both patients who were interested in physician aid-in-dying and those who were uninterested in the option. Fromme's goal was to maintain his ability to care for patients whether they were for or against physician aid-in-dying. In his opinion, physicians should never be in the position of suggesting aid-in-dying as an alternative for a patient. Fromme acknowledged that the necessity of respecting individual health professionals' rights to not be involved in physician-assisted death means that accessibility becomes highly dependent on a health professional's personal stance—in terms of individual providers as well as the entire health care systems. He explained that he maintained a bright line between palliative care and physician aid-in-dying during his time in Oregon, but he said that today he is unsure how important it is for the concepts of palliative care and physician aid-in-dying to be separate in the minds of clinicians, patients, and families. After all, palliative care physicians have the most experience caring for terminally ill patients. Is it reasonable for them to refuse to be involved in or serve as a resource for patients considering aid-in-dying?

Fromme said that there is a tension between non-encouragement and non-abandonment. For a physician who does not want to participate in aid-in-dying, doing nothing could feel like patient abandonment, whereas facilitating a request for aid-in-dying could feel like encouragement. He also said that a physician should take a different approach to handling patients who just want a prescription versus patients who think they

might need a prescription because they are worried about things getting out of control at the end. "Those may sound overlapping, but, in my experience, they are two very distinct groups of people," he explained. He also noted that prognostic uncertainty puts clinicians in a vulnerable position because it is impossible to be entirely certain about when a patient will die, while an event of this magnitude demands a high level of certainty.

In his 15 years in Oregon, Fromme said, he never had a frivolous request for aid-in-dying. He added that he found that patients uniformly respected a clinician's personal moral boundaries about participation and stressed that physicians should be upfront with patients early on if they are opposed so that the patient's time is not wasted. He added that the patients he saw who were not terminally ill were anxious but generally willing to wait and see before considering aid-in-dying. However, patients who did not qualify for aid-in-dying because they did not or would not have decision-making capacity were often angry.

Reflecting on the rarity of psychiatric refusals, Fromme suggested that it is not that oncologists are determining that patients do not have decision-making capacity and thus do not bother referring them to mental health professionals. Rather, Fromme said that in his experience, any physician who is contemplating refusing a request based on a psychiatric diagnosis is going to make sure that a mental health professional makes the determination. He also said that the low rate of psychiatric referrals is in part a reflection of the fact that patients are making serious, as opposed to frivolous, requests. However, he said, in his experience it was apparent to him that some patients were coached on the right things to say and to not talk about symptoms of depression or anxiety.

Fromme commented that access to physician aid-in-dying has been limited in the urban area of Portland, Oregon. Three faith-based health systems and the Veterans Affairs medical center, which together account for the majority of health care services in the city, along with many smaller physician groups adopted policies that forbade their physicians to prescribe lethal medications or to discuss physician-assisted death with patients. This forced patients to either abandon their request or to seek care from one of two health systems that had not forbidden physicians to prescribe. One health system, however, changed its approach over time, he said. In 1997, that institution's policy was to neither encourage nor discourage patients, and it prohibited its physicians from prescribing, serving as consultants, or referring patients anywhere else. In 2004 it updated its policy to allow its physicians to act as consultants and to refer patients to other resources, and in 2018 it decided to allow its physicians to prescribe end-of-life medications. This change in policy, Fromme said, was driven by the institution's ethics committee, which justified the

change based on feedback from physicians who reported that they were being forced to abandon their patients at their greatest time of need.

In rural areas of Oregon, Fromme said, access to physician aid-in-dying is less clear, but the rates of request are low. Access to specialty palliative care is limited or non-existent in rural areas. He reported that many hospice organizations decided not to participate in physician aid-in-dying requests and that many rural physicians said they did not want to become involved in assisted deaths for fear it would alienate some in their communities.

## REFLECTIONS ON PREPARING FOR AND RESPONDING TO LEGALIZATION IN CALIFORNIA

*Barbara Koenig*
*Professor*
*University of California, San Francisco*

On June 9, 2016, California's End of Life Option Act (EOLOA) went into effect, something that was relatively unexpected for anyone who had not been involved in getting the legislation passed, said Barbara Koenig, a professor of bioethics and medical anthropology at the University of California, San Francisco's (UCSF's) Program in Bioethics. From her position as the director of bioethics at UCSF, she experienced the law's passing as a "bioethics emergency" because suddenly institutions across California were challenged with the development of practices and procedures related to physician aid-in-dying. Koenig reported that while it may seem fairly straightforward to implement a relatively simple law, that was not the case.

Koenig's first step was to approach several foundations, and together they convened key stakeholders around California for two meetings. The first, held in December 2015, brought together ethics committees, palliative care programs, and others to talk about the kinds of internal processes they would use as they set up their own policies that would go into effect in the next year. The second meeting, in September 2017, characterized California's response 1 year after the law had been in effect.

This project has produced shared resources, Koenig said, including a project website with videos of the key plenary sessions at the two meetings[7] and a paper summarizing the first meeting (Petrillo et al., 2017). Other members of the EOLOA Task Force are now conducting a survey of California's health care systems' progress in developing and implementing policies concerning physician aid-in-dying. This survey is ongoing,

[7] See http://www.eoloptionacttaskforce.org (accessed March 22, 2018).

and many health systems have not yet developed policies, Koenig said, particularly those in rural areas. Another task force project is currently collecting in-depth patient, family, and provider narratives.

For Koenig and many of her colleagues, there is a sense of moral ambiguity associated with the topic of physician-assisted death. She argued that these moral concerns will not disappear and that if they did, that would be a reason for concern. While she is not opposed to physician aid-in-dying, she said, she has concerns about the practice becoming routine. Similarly, Koenig said, there has been notable ambivalence on the part of many institutions in California, even among those offering the option of an assisted death. There is also the concern, particularly among palliative care providers, about becoming the "go-to" physician or institution for patients requesting assisted death. To gain acceptance as a specialty, palliative care practitioners have had to overcome the idea that only the "dying" can benefit from such care.

Koenig said that an institution must consider a number of issues when determining how to respond to a law such as EOLOA. These consideration include

- Whether to allow the practice on the premises
- Who will participate
- How to honor the conscientious objections by providers while respecting patient choice
- What will be the role of palliative care
- How often will mental health evaluations be conducted
- How to determine if a patient should be referred for an ethics consultations

For example, while most hospitals do not allow the lethal medications to be ingested onsite, patients at a large long-term care institution often have nowhere else to go because the institution is their home. UCSF requires everyone to have a mental health evaluation, but that has created concern among some individuals, Koenig said, particularly those who have advocated for legal change. The issue of who on staff will participate also turned out to be more complicated than a simple yes or no, Koenig said. It often depends on context, including which patient is requesting physician-assisted death, and on other concerns, she said.

In general, she said, implementation has been difficult and uneven, and it requires significant resources, including clearly identified patient navigators. It is also clear that implementation is most practicable when a good hospice and palliative care program exists on which to build. In that regard, Koenig noted one conclusion that came out of her and Neil

Wenger's shared work: physician-assisted death is difficult in places that lack quality hospice and palliative care programs.

One unique provision of the California law is that it has a sunset clause, meaning that it will end on January 1, 2026. As a result, Koenig and the other task force members feel some urgency in thinking about what would help the state decide whether the program should be continued after that time. Another feature of the law is that it requires a "final attestation." As Koenig explained, patients are being asked to sign a document to indicate they are taking the drug before they actually take it, as opposed to when they get the prescription. The data collection efforts surrounding "final attestation" forms are not yet adequate, and therefore it is unknown whether the concept of documenting final ingestion of the lethal medication serves the purpose for which it was intended.

One unique issue that arose at the second stakeholder engagement meeting was that interpreters were being asked to sign documentation attesting to the voluntariness of the patient taking the lethal medication, which many interpreters believe is far out of their scope of practice. Koenig said that the state interpreter association is working on this issue.

The California Department of Health collects the data on the EOLOA, but it is not releasing the data to researchers. Another problem, Koenig said, is that it is hard to capture information about how end-of-life practices are serving or not serving patients from diverse backgrounds. Currently, information about race and ethnicity is captured from death certificates, which Koenig said she has learned from colleagues at the Centers for Disease Control and Prevention is a suboptimal way to capture that information.

Given these difficulties, Koenig said it will be important to develop best practices for collecting data, which will allow her and other researchers to more effectively study the impact of the law on the state's diverse population. Koenig listed several questions that offer opportunities for additional research:

- How are patients with limited social and cultural capital able to navigate the system for requesting physician aid-in-dying?
- What is the effect of the waiting period, and what constitutes an official request? In California, Koenig's team has seen instances where patients think they have made a request—because of conversations with clinicians—but it is not captured in a particular health care system.
- What has been the symbolic impact of EOLOA, and how has passage of the law affected end-of-life care and palliative care for people who are not going to take advantage of physician aid-in-dying?

- Is the desire for physician aid-in-dying part of a broader set of issues concerning the lack of trust people feel in the health care system?
- How can genuine, democratic public engagement around physician aid-in-dying be implemented?

## DATA COLLECTION AND PUBLIC REPORTING

Matthew Wynia said that he became interested in data collection when he and two colleagues noticed that the Colorado physician-assisted death statute had "very thin" data reporting requirements. "We started to wonder why, and then we started looking across the country at other data reporting requirements," he explained. The three of them, he said, realized that there are important ethical, policy, and research questions concerning physician-assisted death—and particularly concerning slippery slopes, the erosion of social and medical norms, barriers to and disparities in access, the frequency of complications arising during the procedure, and the safe disposal of unused drugs—that could only be addressed with good data.

Before he spoke about data sources across the country, Wynia offered his opinion on the matter of physician-assisted death. "Assisted dying is a low-frequency, high-risk medical procedure," he said. "And we should start treating it like that within the medical profession and stop waiting for government and the state to tell us how to manage this." With that on the table, he said that there are three main sources of data on physician-assisted death: physicians (see Table 5-1), patients (see Table 5-2), and pharmacists (see Table 5-3). Some states do better than others when it comes to data collection, with no data collection at all in Montana and the state legislature there having rejected a bill that would have initiated some data collection.

When looking at the data that states collect, there are some obvious gaps, Wynia said. For example, there is no state-collected information on how many patients had to change doctors to access this service. While death certificate data do exist, they are not collected specifically for the purpose of understanding physician-assisted death and do not record when death has occurred following the ingestion of aid-in-dying medications. Data from pharmacists are thin, and data from patients are even more so. Every state except Montana requires that patients fill out a request form and some kind of written attestation from a witness.

No state collects information from patients on their end-of-life concerns and motivations, though California, Oregon, and Washington ask physicians to report patient end-of-life concerns. In fact, published studies that address patient motivations typically get that information from

**TABLE 5-1** Physician-Sourced Data in the Six Jurisdictions Where Physician-Assisted Death Is Legal

| | CO | OR | WA | CA | VT | DC | MT |
|---|---|---|---|---|---|---|---|
| Diagnosis | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Patient's end-of-life concerns (per MD) | | ✓ | ✓ | ✓ | | | |
| Enrollment in hospice | | ✓ | ✓ | ✓ | | | |
| Enrollment in hospice at time of death | | | ✓ | ✓ | | | |
| Health status (ECOG) | | | ✓ | | | | |
| Patient ethnicity/race/ education/insurance | | ✓ | ✓ | ✓ | | ✓ | |
| Which medication is dispensed | ✓ | ✓ | ✓ | ✓ | | | |
| Psychological written report/attestation | ✓ | ✓ | ✓ | | | ✓ | |
| Interpreter used/attestation | | | | ✓ | | | |
| Physician specialty | | | ✓ | | | | |
| Duration of physician–patient relationship | | ✓ | ✓ | | | | |
| Hospital/health system of physician | | | | | | | |
| Physician/other professional present at ingestion | | ✓ | ✓ | ✓ | | | |
| Time between ingestion, unconsciousness, and death | | ✓ | ✓ | ✓ | | | |
| Complications (regurgitation, regained consciousness, EMS activated) | | ✓ | ✓ | ✓ | | | |
| Cause of death (ingestion, illness, other) | | ✓ | ✓ | ✓ | ✓ | | |

NOTES: EMS = emergency medical services; MD = medical doctor. ECOG is a measurement scale used by physicians to assess how illness or poor health impacts a patient's daily living abilities. For more information, see http://ecog-acrin.org/resources/ecog-performance-status (accessed June 21, 2018).
SOURCES: Wynia presentation, February 13, 2018. Data from Abbott et al., 2017.

**TABLE 5-2** Patient-Sourced Data in the Six Jurisdictions Where Physician-Assisted Death Is Legal

| | CO | OR | WA | CA | VT | DC | MT |
|---|---|---|---|---|---|---|---|
| Diagnosis | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Witness attestation | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Document if family informed | | ✓ | ✓ | ✓ | | ✓ | |
| Needed to change physician to access AID | | | | | | | |
| End-of-life concerns/motivation for AID | | | | | | | |
| Final personal attestation of capacity | | | | ✓ | | | |

NOTE: AID = aid-in-dying.
SOURCES: Wynia presentation, February 13, 2018. Data from Abbott et al., 2017.

**TABLE 5-3** Pharmacist-Sourced Data in the Six Jurisdictions Where Physician-Assisted Death Is Legal

| | CO | OR | WA | CA | VT | DC | MT |
|---|---|---|---|---|---|---|---|
| Which medication(s) prescribed | ✓ | ✓ | ✓ | ✓ | | | |
| To whom medication is dispensed | | | | | | | |
| Medication follow-up mechanism | | | | | | ✓ | |
| Pharmacist attestation form | ✓ | ✓ | ✓ | | | | |

SOURCES: Wynia presentation, February 13, 2018. Data from Abbott et al., 2017.

doctors, not from the patients themselves, Wynia said. "I will leave it to you to guess how accurate doctors are at assessing their patient's motivations," he said, "but if you look at other domains of medical care, you have reason to believe that doctors are not perfectly accurate in understanding why patients are making the decisions that they are making." He pointed out that 56 percent of the prescriptions written in Colorado are for a newer medication protocol that costs about $500, compared to approximately $4,000 for secobarbital (Colorado Department of Public Health and Environment, 2018). However, the paucity of data means that little is known about complications and how this not-so-simple regimen is being used.

In Colorado, the light collection burden was a result, in part, of the fiscal note attached to the ballot initiative put before the state's voters. The fiscal note on this ballot measure was $45,000, which is all that the Colorado Department of Public Health and Environment is allocated for data collection, analysis, and reporting. This is just enough money to collect data mandated by the law and nothing else, Wynia said. A second reason for the light data collection burden was that it was seen as being helpful in getting physicians to participate, though Wynia said that he has not heard of physicians complaining about the forms they have to fill out for this procedure. He added that he and his colleagues have been trying to improve data collection in the state, but advocates who supported the law are pushing back against collecting more data. He said he finds that ironic, given that these advocates used data from Oregon to bolster their arguments in favor of the law in Colorado, and better data collection could be used to address issues of unequal access and other concerns of these advocates.

As a final comment, Wynia reiterated his earlier statement that assisted dying is a low-frequency, high-risk procedure, and that health professions should start treating it as such. "It is our responsibility and not the responsibility of the government, and not the responsibility of activists, to establish a national registry and to have standard data reporting elements and reporting requirements," he said. "This is something that our professional associations should be doing."

Katrina Hedberg said that there is a need for data not just on physician-assisted death but on all aspects of end-of-life care. Hedberg indicated support for generating more knowledge about options and decision making at the end of life, although the state government is not necessarily in the best position to collect this information. Research on end-of-life options and decisions might be better collected by those directly caring for these patients, such as hospice organizations or academic health settings, such as those with cancer centers or neurological clinics treating patients with ALS. While she is supportive of this research,

Hedberg said that she and her colleagues at the Oregon Health Authority have made it a policy not to collaborate with outside researchers because of the confidentiality issues they face in dealing with the data reported to the state. Reflecting on how to improve data collection, Hedberg said it will be important to clarify the role of government and academia as Oregon does not provide funding for data collection beyond that required for monitoring and reporting.

In the Netherlands, Bregje Onwuteaka-Philipsen said, the government collects data every 5 years by taking a stratified sample of approximately 6,000 deaths and sending each attending physician a questionnaire with guaranteed anonymity. From a sample of those physicians, the government also conducts follow-up interviews to get more insights, experiences, and opinions from physicians.

Canada's legislation required that the federal minister of health work with the provinces and territories to develop a regulatory framework that focuses on compliance for transparency and public trust, Jennifer Gibson said. So far, she said, the federal government and Health Canada have issued guidelines on death certificates in order to ensure some consistency across the country on how medically assisted deaths are reported. The federal government and Health Canada are also working with the provinces and territories to develop regulations regarding monitoring compliance with federal, provincial, and territorial regulations.

Gibson said that the provinces and territories themselves have been actively involved in developing measures to monitor compliance in their own settings. In fact, she said, some provinces and territories are able to track indicators on access, on the numbers of requests and types of requests, and on reasons for why requests are not granted. The success at gathering this information varies at the local and institutional level, and the data collections systems are not well integrated at this point, but there are conversations and efforts aimed at creating a seamless national data collection system, Gibson said.

The Canadian government's consultations with a wide range of stakeholders has revealed some pragmatic concerns about data collection, she said. The potential burden on practitioners has been raised as a concern, as have concerns about ensuring privacy protection for patients, practitioners, and the pharmacists who dispense the lethal medications. Gibson said that physicians and nurse practitioners have expressed concerns about the clarity of the reporting requirements. She said that these health care professionals want to understand the reporting requirements and how best to meet them.

In Canada, Gibson said, there is an interest in identifying a set of minimum indicators that could be used for the purposes of comparison, sharing lessons, and aligning times for reporting in the context of the

realities of clinical practice. Initially, reports were expected within 10 days, she said, but based on feedback from practitioners, there is a proposal to extend the reporting time to 30 days. Gibson added that there is also interest in using data not only for monitoring compliance but also to better understand which data matter with regard to equity, quality, and the broader social impact of medical aid-in-dying as well as to learn how to gain more insights into patient and public perspectives. In closing, Gibson said she wanted to add her voice to those of the other speakers to say that the research community—not just the government—needs to be involved in data collection. In addition, she said, funders need to support data collection efforts to ensure that any research agenda will be to serve the public interest and to leverage expertise to ensure that the continuum of end-of-life care, and not just medical assistance in dying, is done well.

## REFERENCES


Abbott, J. T., J. J. Glover, and M. K. Wynia. 2017. Accepting professional accountability: A call for uniform national data collection on medical aid-in-dying. *Health Affairs Blog: End of Life & Serious Illness*. https://www.healthaffairs.org/do/10.1377/hblog20171109.33370/full/https://www.healthaffairs.org/do/10.1377/hblog20171109.33370/full (accessed May 24, 2018).

Boring, N. 2014. Belgium: Removal of age restriction for euthanasia. *Global Legal Monitor*, March 11.

California Department of Public Health. 2017. *California End of Life Option Act 2016 data report.* https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx (accessed May 24, 2018).

Chambaere, K., R. Vander Stichele, F. Mortier, J. Cohen, and L. Deliens. 2015. Recent trends in euthanasia and other end-of-life practices in Belgium. *New England Journal of Medicine* 372(12):1179–1181.

Chin, A. E., K. Hedberg, G. K. Higginson, and D. W. Fleming. 1999. *Oregon's Death with Dignity Act: The first year's experience.* Portland: Oregon Health Division.

Colorado Department of Public Health and Environment. 2018. *Colorado End-of-Life Options Act, year one: 2017 data summary.* Denver, CO: Department of Public Health and Environment Center for Health and Environmental Data.

Death with Dignity National Center. n.d. *Frequently asked questions about death with dignity*. https://www.deathwithdignity.org/faqs (accessed April 27, 2018).

Gaster, B., E. B. Larson, and J. R. Curtis. 2017. Advance directives for dementia: Meeting a unique challenge. *JAMA* 318(22):2175–2176.

Gerein, K. 2017. Young patients, their parents now asking for medical aid in dying: Pediatricians' group. *The Edmonton Journal*, October 25.

Hedberg, K., and C. New. 2017. Oregon's Death with Dignity Act: 20 years of experience to inform the debate. *Annals of Internal Medicine* 167(8):579–583.

Lewis, P., and I. Black. 2012. *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. London, UK: King's College London Dickinson Poon School of Law.

Loggers, E. T., H. Starks, M. Shannon-Dudley, A. L. Back, F. R. Appelbaum, and F. M. Stewart. 2013. Implementing a death with dignity program at a comprehensive cancer center. *New England Journal of Medicine* 368(15):1417–1424.

Mullan, F. 2000. Angels in America. *The New York Times*, August 13.

Oliver, P. 2016. *"Another week? Another week! I can't take another week": Addressing barriers to effective access to legal assisted dying through legislative, regulatory and other means.* Thesis submitted to the University of Aukland. https://researchspace.auckland.ac.nz/handle/2292/29864 (accessed May 24, 2018).

Onwuteaka-Philipsen, B. D., M. L. Rurup, H. R. Pasman, and A. van der Heide. 2010. The last phase of life: Who requests and who receives euthanasia or physician-assisted suicide? *Medical Care* 48(7):596–603.

Oregon Health Authority. 2018. *Oregon Death with Dignity Act: 2017 data summary.* http://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx (accessed May 7, 2018).

Ouellette, A. 2017. Barriers to physician aid in dying for people with disabilities. *Laws* 6(4):23. doi: 10.3390/laws6040023.

Petrillo, L. A., E. Dzeng, K. L. Harrison, L. Forbes, B. Scribner, and B. A. Koenig. 2017. How California prepared for implementation of physician-assisted death: A primer. *American Journal of Public Health* 107(6):883–888.

Porter, C. 2017. At his own wake, celebrating life and the gift of death. *The New York Times*, May 25.

Scottish Parliament. 2010. *End of life assistance (Scotland) bill*. http://www.parliament.scot/parliamentarybusiness/Bills/21272.aspx (accessed April 27, 2018).

Snyder Sulmasy, L., and P. S. Mueller, for the Ethics, Professionalism and Human Rights Committee of the American College of Physicians. 2017. Ethics and the legalization of physician-assisted suicide: An American College of Physicians position paper. *Annals of Internal Medicine* 167(8):576–578.

Span, P. 2018. One day your mind may fade. At least you'll have a plan. *The New York Times*, January 19.

Stokes, F. 2017. The emerging role of nurse practitioners in physician-assisted death. *Journal for Nurse Practitioners* 13(2):150–155.

Washington State Department of Health. 2017. *Washington State 2016 Death with Dignity Act report.* https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData (accessed May 24, 2018).

# 6

# Physician-Assisted Death in the Context of Long-Term Services and Supports, Palliative Care, and Hospice

**Key Messages Presented by Individual Speakers/Participants**

- Three-quarters of Americans will need long-term services and supports at some point in their lives, and the prevalence of Americans needing long-term services and supports will double within 15 years. (Lynn)
- Budgetary pressures and an insufficient workforce are creating significant challenges regarding the provision of long-term services and supports to the growing number of older Americans. (Phillips)
- Challenges to physician aid-in-dying for the population in long-term care occur in three areas: assessing cognitive competence, ensuring voluntariness in potentially coercive situations, and defining terminal illness. (Lynn)
- Numerous research and policy gaps exist in understanding how individuals in long-term care view physician-assisted death and their interest in or access to this option. (Phillips)
- The focus of efforts for individuals at the end of life should be on the broader provision of palliative care. (Pasternak)
- Listening carefully to patients about why they are bringing up physician-assisted death now and what they worry about most in the days ahead is critically important. (Pantilat)

- When developing policies for physician-assisted death, institutions should first establish a clear process and support for patients, families, and clinicians. (Pantilat)
- Awareness of last-resort options is important because many people have seen harsh deaths and worry that the same thing could happen to them. (Quill)
- Barriers to accessing physician-assisted death include the lack of an attending physician or supportive family, a lack of mental or physical capacity, challenges in navigating the process, and the high cost of medications. (Campbell, Hansen, Lynn)
- Ethnocultural disparities in accessing hospice, palliative care, and physician-assisted death are not fully understood, but factors include mistrust of the medical system based on past abuses, religious beliefs, and disparities in communication and health care planning. (Berger)
- Studies of the values identified by hospice and palliative care programs in determining their policy about physician-assisted death find that the value of patient self-determination ranked highest along with the relief of pain and suffering. (Campbell)

NOTE: These points were made by the individual speakers/participants identified above. They are not intended to reflect a consensus among workshop participants. The statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

## LONG-TERM SERVICES AND SUPPORTS

### Context and Gaps: Long-Term Services and Supports in the United States

*Joanne Lynn*
*Director, Center for Elder Care and Advanced Illness*
*Altarum Institute*

*Cheryl Phillips*
*President and Chief Executive Officer*
*Special Needs Plans Alliance*

Most Americans will need long-term services and supports at some point in their lives, said Joanne Lynn, the director of the Altarum Institute's Center for Elder Care and Advanced Illness, and the current prev-

alence of Americans needing these services and supports will double within 15 years (Favreault and Dey, 2016). Cheryl Phillips, the president and chief executive officer of the Special Needs Plans Alliance, provided an introductory overview and reported that currently more than 12 million people use long-term services and supports (Anthony et al., 2017), with long-term care occurring in many settings, including at home and in skilled nursing facilities, rehabilitation facilities, long-term care hospitals, nursing homes, and assisted living facilities. How care is paid for in these settings depends on specific Medicare and Medicaid regulations as well as on an individual's personal finances. Phillips said that long-term services and supports include custodial, residential, and community-based services, the majority of which are private pay. Some states are moving to managed Medicaid long-term services and supports.

Long-term care is expensive, Phillips said, with the average nursing home stay costing around $84,000 per year and the average assisted living facility costing approximately $44,000 per year (Genworth Financial, 2016). She said that in-home care averages $150 for 8 hours, with an average annual cost of $46,000. For the United States as a whole, long-term care costs $275 billion annually (Pennsylvania Health Care Association, n.d.). States are moving quickly to managed long-term services and supports as they face increasing budget challenges and look to cut back on Medicaid benefits. These services, Phillips said, are typically funded under waivers and are not typically considered a Medicaid essential benefit. Medicaid reform, she added, is likely to involve block grants, further limiting funds available for long-term services and supports. Contrary to what many in the public believe, she said, Medicare only pays for "skilled services" and not "daily support services" or personal care.

Lynn said that most Americans do not have plans for covering the anticipated 2-year duration of self-care disability, given that the average person entering retirement has no retirement savings beyond Social Security (Morrissey, 2016). As a result, she said, "we have enormous numbers of people coming to old age without adequate retirement security, without assets, and facing long-term disability," and the burden of providing long-term services and supports to most Americans will fall on family and friends who are also getting older.

Lynn said that the nation's support for long-term care and geriatric care is, in her opinion, woefully inadequate. Despite increases in Medicare spending and increasing numbers of older Americans, federal spending on long-term services and supports under the Older Americans Act has fallen and is now flat (see Figure 6-1), with proposals for further cuts. Lynn noted, too, that the United States spends nearly twice as much on medical care and about half as much on social supports as the average

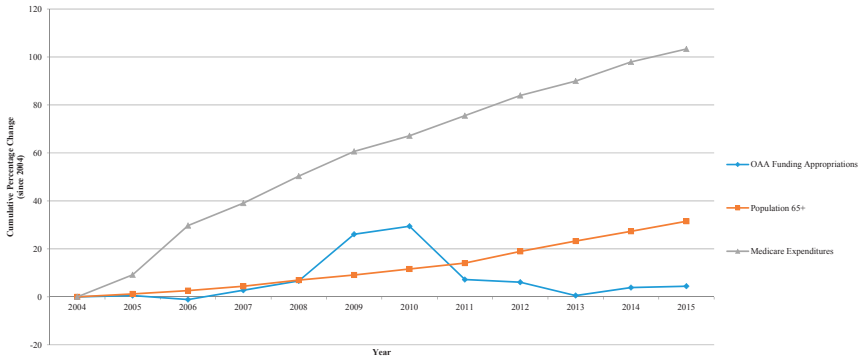


**FIGURE 6-1** Federal funding for the Older Americans Act (OAA), Medicare expenditures, and the population of Americans age 65 and older.
SOURCES: Lynn presentation, February 13, 2018. Data from Parikh et al., 2015.

spending of Organisation for Economic Co-operation and Development countries (Bradley and Taylor, 2013).

Adding to the challenges of providing long-term care for those in need is the fact that the workforce is insufficient to meet demand. Phillips suggested the direct care workforce will need to increase 50 percent by 2030 to meet anticipated demand. Few clinicians are prepared to work in a palliative care setting or are trained in geriatrics. A few states have minimum staffing requirements for long-term care facilities, but most states do not set minimums. As a result, Phillips said, one direct care worker may have to deal with as many as 18 people, with perhaps one licensed practical nurse on a unit and a registered nurse available only during the weekdays. There seems to be an expectation, Phillips said, that families, who are already burdened and already provide uncompensated care valued at $450 billion annually (Family Caregiver Alliance, 2015), will fill in the gaps; however, as she noted, most families do not know how to approach providing the kind of care many individuals will require. In addition, forcing families to provide long-term care will translate into additional losses of income, retirement benefits, and opportunities for promotion that the caregiver could have had at work, which in turn will often compound the financial stress many families experience both before and after their family member is gone.

## Physician-Assisted Death and Long-Term Services and Supports

*Cheryl Phillips*
*President and Chief Executive Officer*
*Special Needs Plans Alliance*

*Joanne Lynn*
*Director, Center for Elder Care and Advanced Illness*
*Altarum Institute*

*Barbara Hansen*
*Chief Executive Officer*
*Oregon Hospice and Palliative Care Association*

Data on physician-assisted death in long-term care are virtually nonexistent, Phillips said. Anecdotally, many nursing homes have policies against allowing physician-assisted death to occur onsite due to concerns about licensing and certification, among other issues. However, Phillips noted, data may not be collected on where the medication is taken. For example, California does not require "location of ingestion" to be reported.

Lynn said that challenges to physician aid-in-dying for the population in long-term care occur in three areas: (1) assessing cognitive competence, (2) ensuring voluntariness in potentially coercive situations, and (3) defining terminal illness (see Chapter 2 for more discussion on terminal illness). Regarding voluntariness, she said that many older individuals face impoverishment and the loss of their legacy as they dispose of their assets to become eligible for Medicaid and secure long-term services and supports. The potential for conflicts of interest with respect to nursing homes is also an issue that must be considered, Lynn emphasized. Almost all nursing homes are either for-profit (and therefore must pay their shareholders) or owned by a city, county, state, or other community, which are often financially strapped. Regarding cognitive abilities, Phillips said that between 50 and 70 percent of residents in long-stay nursing homes and assisted living facilities have documented dementia (Harris-Kojetin et al., 2016), and the level of cognitive impairment in those settings is thought to be even higher. On the other hand, the rates of dementia and cognitive impairment in home- and community-based services settings for long-term care are not known, she said.

Speaking about the barriers to accessing physician-assisted death for individuals in long-term care, Barbara Hansen, the chief executive officer of the Oregon Hospice and Palliative Care Association and the executive director of the Washington State Hospice and Palliative Care Organization, said that individuals who lack an attending physician or family or

friends who can serve or are willing to serve as witnesses find it difficult to pursue this type of death. Faith-based providers of long-term services and supports often do not allow physicians to participate, and for some residents in nursing homes, lack of mental capacity can be a barrier. Waiting too long and losing the capacity to self-medicate can be a barrier, as can the fact that most long-term care facilities do not allow the practice to take place onsite.

Phillips emphasized that the waiting list for many Medicaid-covered long-term care sites is quite long and that for every opening in subsidized senior housing, there are 10 seniors waiting; most will die before they are accepted. Combined with the financial challenges, these factors have the potential to create subtle—and not-so-subtle—pressures on older individuals to consider physician-assisted death. Additionally, many older people and their families have not discussed among themselves or with their health care providers the full range of options for addressing symptoms, managing the end of life, or developing care plans that fully reflect the individual's wishes. Lynn said that a national dialogue and action are needed to support older individuals and their long-term care needs. Society does not care about this part of life and chooses not to talk about it, she said, even though the majority of people will go through this part of life.

To illustrate the range of issues and concerns specific to physician-assisted death, Lynn read a statement from the American Geriatrics Society in its amicus briefs for the *Vacco v. Quill*[1] and *Washington v. Glucksberg*[2] cases:

> Most elderly persons experience serious and progressive illness for extended periods before death and need significant social, financial, and medical supports. These resources too often are not available. . . . By collaborating in causing early deaths . . . geriatricians would become complicit in a social policy which effectively conserves community resources by eliminating those who need services. By refusing . . . because a patient's relative poverty and disadvantaged social situation is seen as coercive, geriatricians would condemn their patients, and themselves, to live through the patients' undesired difficulties for the time remaining. . . . Elderly and frail persons would be put at risk [with physician-assisted death being available], yet their interests and concerns have not been adequately addressed in the public discussion. p. 491. (Schmitz et al., 1997, pp. 491–499)

While long-term care is getting some attention, primarily because of the managed Medicaid aspects, Phillips said, there are numerous research

[1] *Vacco v. Quill*, 521 U.S. 793 (1997).
[2] *Washington v. Glucksberg*, 521 U.S. 702 (1997).

and policy gaps in understanding how this population views physician-assisted death and their interest in or access to this option. Phillips noted that the current focus for physician-assisted death has been for younger people with more predictable courses of disease, such as with cancer or amyotrophic lateral sclerosis (ALS), and that little, if any, attention is being paid to the oldest who are grappling with frailty and lack of available support systems and care. Phillips questioned whether the focus should be on how to improve palliative care in the long-term care setting, instead of on physician-assisted death.

Lynn listed a number of research questions relevant to long-term care and physician-assisted death, including

- What are the current practices in long-term care settings regarding physician-assisted death in locations where it is legal?
- What are the financial, emotional, and other pressures being faced by older individuals using long-term services and supports, and how do they affect considerations of physician-assisted death?
- What are the potential and realized conflicts of ethics and values for providers of long-term care?
- Who will sponsor the research that is needed?

Hansen offered a list of topics for potential future research regarding the impact of physician-assisted death:

- Do any patients complete physician-assisted death because symptoms are not being managed?
- Is there a difference in the grief process for survivors of a person who completed physician-assisted death versus survivors of a person who died a natural death?
- How does caring for a person who completed physician-assisted death affect health care providers in the long term? Does it contribute to more or less "burnout"?
- How does the impact of physician-assisted death on families and health care providers compare to the effects when patients use other means of self-inflicted death?
- What is the impact on patients and families if their hospice program has a policy that does not allow their staff to be present in the home when the patient takes the medication?

## HOSPICE AND PALLIATIVE CARE

Citing data from the Oregon Public Health Division, Hansen said that as of 2016, nearly 90 percent of patients using physician-assisted death were enrolled in hospice, and the great majority of deaths under Oregon's Death with Dignity Act took place in the hospice patient's home (Oregon Health Authority, 2017).

### Experiences and Policies

Workshop speakers described a variety of experiences with physician-assisted death in hospice and palliative care and detailed a range of policies developed by their institutions.

*Stephanie Harman*
*Clinical Associate Professor of Medicine and*
*Clinical Chief of Palliative Care*
*Stanford University School of Medicine*

When Stanford Medicine deliberated as an institution about how it would participate in California's new medical aid-in-dying law, the process was led by the institution's ethics department, said Stephanie Harman, a clinical associate professor of medicine at the Stanford University School of Medicine and the clinical chief of palliative care. This process included 20 town hall meetings which provided a broad perspective on what the medical staff thought about physician-assisted death as well as on the role that palliative care should be playing from an institutional perspective. Clinicians who were supportive of the legislation but did not want to be involved in the process thought that palliative care physicians should be the sole providers of the prescriptions, a position with which Harman and her colleagues in palliative care disagreed. Harman explained that she and her colleagues did not want to be in the official position of prescribing lethal medications but rather wanted to strive to facilitate dialogue in the process.

Clinicians who were opposed to the law said that if Stanford Medicine was going to participate, there should be as many safeguards put into place as possible. A third group wanted to keep others from being involved in the decision as a means of maintaining their relationship with their patients. In their view, no policy was needed. The one thing that everyone agreed on, Harman said, was that patients requesting physician-assisted death have palliative care needs.

When Stanford implemented its policy on physician-assisted death, it added a few features that were not required in the law. For example, Stanford's policy requires an ethics consultation following the initial

patient request. The ethics consultants provide support and resources, serve as navigators, and answer questions. They also help the patient connect to social workers who can direct the patient to a physician who is willing to prescribe in the case where the patient's usual clinician will not. Stanford's policy also requests completion of an advance directive and physician order for life-sustaining treatment forms if those have not already been completed.

Palliative care participated fully in the process of developing these institutional policies, Harman said, and is a required part of the physician-assisted death process at Stanford. Palliative care physicians who choose to participate take on the role of the willing consulting physician, she said, which involves both serving as the consulting physician and helping the patient explore any available options that may not have been discussed previously (palliative care physicians can also decline to serve as the consulting physician, as per the law). Palliative care also conducts a physical, social, emotional, and spiritual assessment of the patient, and it provides a wide range of services to both the patient and family members.

Harman said that the institution had to develop an overall approach for triaging patients who wanted to access physician-assisted death. There is a sense of urgency for scheduling these appointments, not just for the patients but also for attending physicians. At the same time, she said, there was a concern as to whether that urgency should trump the needs of patients who are coming into clinic for acute symptom management. She also said that many patients are seeking aggressive, innovative treatments that may be available to them through clinical trials and which may extend their life beyond a 6-month prognosis, while also seeking physician-assisted death as a backup plan. Reconciling those desires for continued disease-directed care and the option of physician-assisted death has been challenging, Harman said. She said that the key lesson thus far has been to elicit all voices in the conversations about physician-assisted death, and to listen. As a final note, she said that by codifying palliative care into Stanford's physician-assisted death process, palliative care has become more widely recognized across the institution as a resource and source of support for clinicians, patients, and families going through a very difficult experience.

### *Gary Pasternak*
### *Medical Director*
### *Mission Hospice and Home Care*

Saying that his views have been shaped by his 20 years of experience as a practicing palliative care and hospice physician, most of it at a small, nonprofit, community-based hospice in San Mateo, California,

Gary Pasternak, the medical director at Mission Hospice and Home Care, said that he has a fairly neutral view about physician-assisted death and, like many palliative care physicians, believes that the focus of efforts should be on the broader provision of palliative care.

When California passed the End of Life Options Act (EOLOA), he said, his organization responded quickly to the new law, holding several months of brown bag discussions, forums, and meetings to educate itself about the law and find out how staff felt about it. An interdisciplinary committee that included non-clinical staff took the feedback from these activities and wrote a policy defining what EOLOA meant to the agency and its staff members, knowing it would be a work in progress. An important part of developing this policy was to establish ongoing support groups for staff, facilitated by the spiritual care and social work staff.

The essentials of the resulting policy included the decision for the agency to opt in and meet patients where they are, but to never suggest or recommend EOLOA to patients. The policy states that only one of the physicians (either the consulting or attending physician) involved in a patient's request for physician-assisted death can come from the hospice and that multidisciplinary involvement would always be offered and encouraged. Any staff member can refuse to participate without any repercussions, and a patient having been admitted to the hospice does not obligate the agency to provide this end-of-life option to the patient. A counselor is available for any team member requesting it. The agency provides ongoing education, evaluation, and support.

The organization had its first request for physician-assisted death within 24 hours of the law going into effect, Pasternak said, and it was one of his own patients. Pasternak said that he decided to assist his patient with her request after seeking mentoring and counseling from an Oregon physician who had many years of experience. Pasternak said that after multiple meetings with the patient, a 93-year-old lawyer with lung cancer who was failing rapidly, and the patient's family, he had no question in his mind that she was clearly a candidate for the procedure. He was present for her ingestion of the lethal medication, and he noted that he "found the experience compelling in its peacefulness, the sense of relief and completion for the family, and in the remarkable value of the presence of the hospice staff."

Based on this and subsequent experiences, Pasternak said, it is his hospice's practice to have as many team members present as the patient and family will allow, but almost always a physician and a nurse. No family has refused this offer of assistance and support, and almost every family welcomes the presence of hospice staff. He said he feels that this

is one of the best aspects of the practice that he and his colleagues have developed in that they do not just prescribe the medication, but they also see the process through.

So far, he said, his organization has served some 40 patients, gaining a great deal of experience in the process. That experience has taught Pasternak that hospice, with its whole-person and family approach to end-of-life care, is uniquely situated to be part of these dying experiences. Quoting a member of his staff, one of the EOLOA group facilitators, he said, "Engaging with EOLOA has had a profound impact on our staff. The common response is one of awe, along with humility and gratitude for the privilege of witnessing such a peaceful passage."

Pasternak then described two different trajectories and levels of involvement with the hospice and requests for physician-assisted death. In one case the patient, a 97-year-old woman who was the matriarch of a large family and a strong advocate for the California law, began talking about physician-assisted death as an option about a year before the law was passed. She had lived in a large assisted-living facility for many years, and when she was diagnosed with a terminal illness, her goals of care were clear, and her primary care doctor honored her request for EOLOA and agreed to be the prescribing physician. One week before her final day, her assisted living facility had developed a policy that allowed this to occur at the facility. On her final day, she had each member of her family come into her room for one last goodbye and to provide one last bit of advice. There were tears mixed with laughter as they all gathered, Pasternak recalled, and she passed away peacefully. One of her daughters later wrote a note to Pasternak and his colleagues expressing her family's deep gratitude.

Another patient, a 72-year-old woman with ovarian cancer, was interested in getting the process of requesting physician-assisted death going quickly as her health was failing and she was concerned about the care options. However, with time she became more ambivalent about dying and about taking the medications. Her family did not support her interest in pursuing assisted death. Pasternak said that the patient wanted him to decide for her, and it became one of her biggest burdens that she had this choice. When she became too frail to remain in her home, she was transferred to the agency's hospice house, and the comprehensive application of palliative care in a multidisciplinary hospice setting met her needs. She never took the medication. Pasternak said, "I think the simple and constant presence of the entire staff basically supported her as a person beyond the confines of her illness, so her illness and her suffering were not what totally defined her."

One of his main concerns with physician-assisted death, he said,

is that it may be contributing somehow to premature closure. For this patient, intensive palliative care was extremely helpful, and she had a very peaceful death without intractable symptoms.

*Steven Pantilat*
*Kates-Burnard and Hellman Distinguished Professor in Palliative Care*
*University of California, San Francisco*

The approach that the University of California, San Francisco (UCSF), is taking in response to California's EOLOA, said Steven Pantilat, a professor of medicine, the Kates-Burnard and Hellman Distinguished Professor in Palliative Care, and the director of the Palliative Care Program and Palliative Care Quality Network at UCSF, is that people who request the EOLOA option need palliative care. At the same time, he said, he and his colleagues feel strongly that palliative care is not to be equated with the end of life. In fact, he said, the palliative care team has worked assiduously over many years to disconnect palliative care from the end of life and move it upstream.

After extensive discussions, Pantilat continued, his team decided that it did not want everyone requesting assisted death to get a mandatory referral to palliative care. Most, but not all, of the palliative care physicians on the team did decide to be willing to serve as the consulting physician for most patients and as the prescribing physician for longstanding patients. A consulting physician's focus is on confirming a prognosis of limited time, discussing options with the patient and family, and determining if the patient has the capacity to make the decisions. However, it was clear, Pantilat said, that nobody wanted to be the "go-to" physician for physician-assisted death requests.

As UCSF developed its institution-wide policy, it started from the premise that, as a public institution, it would participate in the options provided in the law. Developing the policy was a lengthy process in which a great deal of input was solicited, with the underlying knowledge that the final policy would be a model for the state. Pantilat said that he and his colleagues never assumed they were creating a perfect policy, only that other institutions in the state would look to UCSF.

One aspect of UCSF's policy is that participating in EOLOA requires viewing an educational slide set and passing a test to receive a designated medical staff privilege. One of the two physicians participating in a physician-assisted death request must have that privilege. UCSF's policy also mandates a psychiatric referral so that potential mental health issues in the candidate population are not overlooked. Pantilat acknowledged that this makes an already burdensome process more so, and in some

cases, when it is clear that the patient and family support the decision strongly, the referral requirement is waived. At UCSF, social workers are the point of contact for information, but they are not navigators because they do not walk patients through the entire process.

UCSF's experience has been that few physicians have agreed to participate in the program, and the institution does not keep a list of those physicians who are willing. Nearly all patients interested in physician-assisted death are enrolled in hospice, he said. In general, the process is difficult for patients, especially for those with neurologic conditions. From Pantilat's experience as a palliative care physician who has worked with ALS patients, he said that by the time most patients with ALS have a clear 6-month prognosis, they are not able to take the medication. He also said that pharmacies and pharmacists are crucial partners in the process and that it is vital to ask questions of patients and listen carefully to their answers about why they are bringing this up now and what they worry about most in the days ahead.

Pantilat recommended that institutions developing policies in response to physician-assisted death laws should prioritize establishing a clear process and support for patients, families, and clinicians. Partnering with hospice and with pharmacists is also important, as is identifying physicians who are willing to prescribe. In his opinion, he said, the best scenario would be to identify two physicians, supported by an interdisciplinary team, to do the prescribing and take referrals, but his organization has not achieved that yet. It is important, he added, to trust the clinicians who agree to participate, while also looking for potential abuses that might arise if all prescribing is concentrated among a few physicians who might look at prognosis or capacity differently. Pantilat said that identifying two physicians to play the primary role in all physician-assisted death requests would require caution but would likely provide better access for patients and families.

Pantilat also suggested that all patients requesting physician-assisted death be referred to palliative care. He said that one benefit of EOLOA has been that people are being referred more often to UCSF's palliative care service. He described the experience of a 94-year-old patient who was interested in assisted death but whose daughter did not support that option. The woman received palliative care and was prescribed the lethal medications but died peacefully before the date she had set to take the medications. Pantilat said that the EOLOA experience did lead this patient to get the care she really needed.

*Timothy Quill*
*Thomas and Georgia Gosnell Distinguished Professor in Palliative Care*
*University of Rochester*

Timothy Quill, the Thomas and Georgia Gosnell Distinguished Professor in Palliative Care at the University of Rochester Medical Center, said that fundamental access to health care—meaning the full range of disease-directed treatment as well as adequate palliative care, decision-making assistance, and sometimes assistance with end-of-life decision making—is essential. Hospice fits into health care as both a philosophy of care and as a medical benefit, he said, but he cautioned against telling dying individuals that hospice is 100 percent effective at relieving suffering. "We have to learn how to acknowledge the exception," he said. "Sometimes the exceptions are uncontrolled physical symptoms, for example, pain and shortness of breath. Other times they are unrelieved psychosocial, existential, and spiritual suffering."

Awareness of last-resort options is important, Quill said, because many people have seen harsh deaths and worry that could happen to them. For some people, knowing what the options are for ending life gives them a sense of reassurance; most often the options are not exercised even when openly available. Quill mentioned data from Oregon showing that one in six individuals in palliative care or hospice talk about life-ending options with their families, though he guessed that even more individuals probably think about these options but do not raise them with their families. One in 50 talks about these issues with their physician, he said, and in Oregon 1 in every 300 deaths of people enrolled in palliative care or hospice is from medical aid-in-dying (Tolle et al., 2004).

Quill said that it is important to try to ensure that all palliative care alternatives have been examined and exhausted and then, if necessary, to look for the best ways to respond to a patient requesting aid-in-dying that respects the values of the major participants. It is also important to ensure that a patient has full informed consent and active participation of close family members. Quill listed the range of last-resort options, roughly ordered by how much societal agreement exists about their acceptability:

- accelerating opioids to sedation for pain or dyspnea
- stopping life-sustaining therapies
- voluntarily stopping eating and drinking
- palliative sedation, potentially to the point of unconsciousness
- physician-assisted death
- voluntary active euthanasia

Quill said that voluntarily stopping eating and drinking requires tremendous discipline and usually takes 1 to 2 weeks to result in death. This option is probably legal, he said, though it has never been tested in the courts. Providing palliative sedation to the point of unconsciousness can also take days to 1 week or more to result in death, usually from dehydration or a complication of the sedation, but the patient is generally unaware of the suffering.

Quill said that providing palliative sedation to the point of unconsciousness varies widely among palliative care and hospice practices. There are palliative care programs, he said, where patients are frequently heavily sedated at the very end, and there are places that almost never provide sedation. He said he believes that this variation in practice is more a reflection of physicians' values than of the values of the patient. Quill suggested that the same kinds of safeguards that are applied to physician aid-in-dying cases should be considered for palliative sedation. He also suggested that the risks cited for physician-assisted death are present to a greater or lesser degree for the other last-resort options as well.

In New York, where physician-assisted death is not legal, there are organizations that support more potentially life-ending options, which raises the question of whether hospice or palliative care clinicians should tell patients who are interested in these options about those organizations or withhold that information. These organizations do advocacy work and provide information and counseling. They also often provide a presence for individuals who are considering a last-resort option.

In closing, Quill emphasized the importance of information being available to patients about the full range of last-resort options, including what their own physicians legally and personally can and cannot do.

## Studies and Informal Surveys of Hospice and Palliative Care Programs and Physician-Assisted Death

*Courtney Campbell*
*Hundere Professor of Religion and Culture*
*Oregon State University*

Courtney Campbell has conducted research on hospice and palliative care program policies regarding physician-assisted death in Oregon (Campbell and Cox, 2010) and Washington (Campbell and Black, 2014). Some hospice programs—more than 35 percent in Oregon and 20 percent in Washington—identified as non-participating, he said, largely because of religious considerations, though some non-religious programs have decided that physician-assisted death was outside of the scope of hospice care as they defined it. No program that identified itself

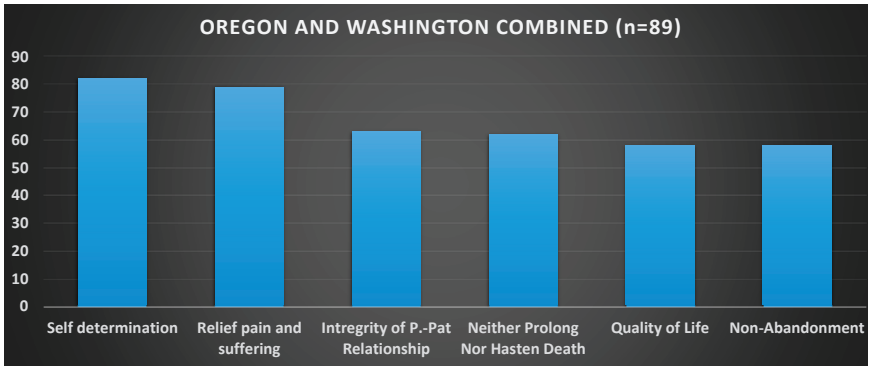


**FIGURE 6-2** Primary values of hospice physician-assisted death policies.
NOTE: P.-Pat Relationship = physician–patient relationship.
SOURCE: Campbell presentation, February 12, 2018.

as non-participating indicated that it would discharge a patient from hospice care because that patient made a request or inquiry or had a conversation about physician-assisted death. A second group of hospice programs—approximately 30 percent in both states—were generally neutral on physician-assisted death and treated it as an issue between the physician and patient. The third group of hospice programs engaged in what they called "respectful participation." These programs—nearly 35 percent in Oregon and 45 percent in Washington—said they respected patient choices and the integrity of the physician–patient relationship. They also respected the decisions of clinicians to not continue to provide care because of contentiousness or religious considerations.

Campbell also examined the values underlying these positions (see Figure 6-2). When hospices were questioned about the principles they relied on in crafting their physician-assisted death policies, patient self-determination was mentioned more than any other, while the value of neither prolonging nor hastening death—a pillar of hospice philosophy—ranked fourth. Non-abandonment was also an important consideration, though 55 of the 89 hospice programs in Oregon and Washington that Campbell examined prohibited hospice staff from being present at the time of ingestion and death.

## Ethnocultural Disparities and Physician-Assisted Death

*Jeffrey Berger*
*Chief, Division of Palliative Medicine and Bioethics*
*New York University Winthrop Hospital*

In his presentation, Jeffrey Berger, the chief of the Division of Palliative Medicine and Bioethics at the New York University Winthrop Hospital and a professor of medicine at the Stony Brook University School of Medicine, said that physician-assisted death is disproportionately a concern of well-educated whites, an observation that he believes should stimulate some questions. At the same time, he said, there are disparities and distrust in palliative medicine, as there are in health care in general. These disparities and distrust, he added, have well-founded historical roots in both explicit and implicit racially based discriminatory practices (Williams and Wyatt, 2015).

In palliative care, Berger said, the literature suggests that African Americans are more likely than whites to have a preference for more life-sustaining therapies regardless of prognosis, and African Americans are less likely to assign a health care proxy or complete a living will out of concerns that these legal documents will be used against them in some fashion (Crawley et al., 2000; Johnson, 2013). African Americans are also less likely than whites to use hospice care and more likely to leave hospice care once they have begun using it. African Americans have less knowledge than whites about palliative care and are, because of spiritual and religious beliefs, less likely to embrace the goals of palliative care. African Americans also tend to have poorer pain control options, with one study finding that people of color in general have less access to pain medications because the pharmacies in their communities tend to stock those medications less often than in white communities (Morrison et al., 2000).

Berger said that the literature disagrees on the reasons for these disparities (Lichtenstein et al., 1997; Loggers et al., 2009; Mack et al., 2010; Volandes et al., 2008; Wasserman et al., 2016; Welch et al., 2005). The reasons that various researchers have posited based on assorted studies include mistrust of the health care system, religious beliefs, health literacy differences, disparities in effective communication and care planning, and disparities between palliative and hospice care teams and minority populations. These studies, Berger said, are limited and offer an unclear consensus, with potential confounding by health literacy considerations. There is a need for improved methodologies to be used in these types of surveys.

One thing that Berger said she worries about is the potential that physician-assisted death has for stimulating greater suspicion and mistrust among underserved populations, leading to further disparities

in care. He noted that this is speculation, as there are no data on this matter. To promote evidence-based health and social policy, Berger recommended that these considerations should be studied in jurisdictions where physician-assisted death is permitted. He added that California, as a demographically diverse state, will provide an important source of data for answering questions about disparities in accessing not only physician-assisted death, but palliative care and hospice as well.

## DISCUSSION

### Vulnerable Populations

A workshop participant with experience as a palliative care nurse in Baltimore said she had felt uncomfortable when hearing in some presentations and workshop discussions that patients must be very persuasive in convincing their physician of the seriousness and legitimacy of their request for aid-in-dying. She said that she has seen that an already unequal power dynamic exists between patients from a vulnerable or minority population and their physician and that she is not surprised that few patients take this option, given the challenges of navigating the system as well as the need to persuade providers in multiple situations that this is the right approach for that individual patient. Quill agreed that the challenges facing vulnerable populations are significant and said that the challenges include the fact that a patient risks being labeled as suicidal by attempting to go through this process—a label that could have very negative consequences for the patient. Quill is struck by the tension surrounding the issue of whether every patient needs to hear that physician-assisted death is an option. He suggested that doing so could frighten many patients and dramatically increase distrust of the medical system. The challenge, he said, lies in determining how physicians can bring up physician-assisted death in a way that is acceptable to a patient and appropriate given their circumstances.

Barbara Koenig of UCSF reflected on the power dynamics inherent in the patient–physician relationship for regular medical care. For instance, are there levels of coercion related to pursuing aggressive cancer treatment? In terms of when to raise the topic of assisted death with a patient, Koenig suggested that possible "trigger" phrases from a patient, such as speaking of a fear of future suffering or requesting to know all of the options as the end of life nears, can indicate to a physician it is appropriate to discuss physician-assisted death.

A workshop participant asked about the recent Washington, DC, decision on physician-assisted death in light of a population and city government that is largely African American as well as concerns about

the legacy of health disparity. Berger said that he was not familiar with the determinations and the approval process in the District of Columbia and emphasized the need to understand the drivers of interest on both sides of the issue of physician-assisted death.

Christopher Kearney, the medical director for MedStar Health Palliative Medicine, said that he had been surprised that physician-assisted death was legalized in Washington, DC, and questioned whether the legalization would have been successful if the measure were voted on by ballot referendum as opposed to a city council vote. His experience as a physician in nearby Baltimore would indicate that there would not be support for such a law, he said. As MedStar has locations in Washington, DC, as well, the institution is facing the challenge of how to respond to the recent legalization of physician-assisted death. Kearney reported that MedStar has not made a decision yet as to the position the institution will take on physician-assisted death, but he said that the company has stated that no one should request aid-in-dying for lack of quality palliative care. He challenged workshop participants to consider a perhaps more useful requirement for hospice care for patients requesting aid-in-dying, as opposed to the current legal requirements for mental health evaluation.

### Institutional Responses

Scott Halpern of the University of Pennsylvania asked whether, despite the relative unease of individual physicians in becoming the "go-to" physician for assisted-death referrals and prescriptions, it would not be the unambiguously right approach to have a few physicians conduct the process for patients all the time. Halpern suggested that having "go-to" physicians who are well supported and trained in the nuances of physician-assisted death would build much needed expertise and could result in a better experience for patients and families. In addition, if physicians were willing to be involved in assisted-death requests for patients some of the time, then they must not have a conscientious objection to the practice, in which case it could be a better allocation of resources to have a few physicians be involved in all the assisted-death requests at a particular institution. He reflected on his experience as a critical care physician in the United States during the Ebola epidemic. Because the U.S. cases of Ebola were rare, it did not make sense for every physician at his hospital to be trained in the appropriate precautions, he said, so a few physicians volunteered to take on this training for the institution. Pantilat responded that there are physicians willing to be the "go-to" in his area of California, but none of them are at his institution. UCSF physicians do sometimes refer patients to the few physicians in the area who participate in assisted deaths frequently. Pantilat suggested that in order for a few physicians

to succeed at this they would need the support of a team—including a social worker, nurse, and chaplain working together. Pantilat also suggested that some of the unease among physicians may be related to the newness of physician-assisted death, and he suggested that over time physicians may become more comfortable with it. Harman responded that at Stanford there are physicians who are willing to prescribe for their own patients as well as willing to prescribe for other physicians' patients. While these physicians are not known as the "go-to" doctors, those who do have experience as prescribers serve as resources to guide physicians new to the process.

### Professional Societies

Workshop participant Christopher Kearney of MedStar Health asked whether it would be beneficial for the United States to follow the example of the Dutch medical professional societies that have created specialized panels surrounding aid-in-dying in order to deploy standards in this process. He asked why U.S. medical societies have been largely silent or unengaged in the issue of aid-in-dying. In a similar vein, Rebecca Spence, the ethics counsel for the American Society of Clinical Oncology, asked the participants to comment on the role of professional societies in addressing physician-assisted death. Lynn responded that on the broader issue of supporting long-term services and supports, few of the professional societies have spoken up in support of these issues. Regarding physician-assisted death policies, Lynn said, there could be efforts by professional associations into developing a relevant policy by receiving a wide range of input and having extensive discussions (as discussed by several representatives of hospital and hospice systems in Chapter 5).

### Concerns Regarding Underfunded Long-Term Services and Supports

Lynn said—and was echoed by Ron Motley, a geriatric psychologist in northern Virginia, and by John Kelly from Not Dead Yet—there are looming concerns about nursing home, home care, and long-term care costs for our society and its older and disabled members.

Lynn said that a way forward for the United States could be to move resources from the overfunded medical care side to the underfunded long-term services and supports side, but that would be dangerous because it would risk losing the open-ended entitlement for medical care in this country. She indicated that returning some control over these expenditures to geographic localities could be part of a solution and said that it is an approach that almost every other country takes. She cautioned that in this scenario there would still be limits, of course, as it is estimated to

cost $250,000 to support an individual with 24-hour care at home for 1 year, and therefore it is unlikely that everyone who could benefit from this level of care would be able to receive it (Lynn, 2016). The country has not yet had serious discussions about these costs and what the limits are, Lynn said, but the conversation should be forced before the baby boomer generation retires en masse.

## REFERENCES


Anthony, S., A. Traub, S. Lewis, C. Mann, A. Kruse, M. H. Soper, and S. A. Somers. 2017. *Strengthening Medicaid long-term services and supports in an evolving policy environment: A toolkit for states*. Hamilton, NJ: Center for Health Care Strategies.

Bradley, E. H., and L. A. Taylor. 2013. *The American health care paradox: Why spending more is getting us less*. New York: PublicAffairs.

Campbell, C. S., and M. A. Black. 2014. Dignity, death, and dilemmas: A study of Washington hospices and physician-assisted death. *Journal of Pain and Symptom Management* 47(1):137–153.

Campbell, C. S., and J. C. Cox. 2010. Hospice and physician-assisted death: Collaboration, compliance, and complicity. *Hastings Center Report* 40(5):26–35.

Crawley, L., R. Payne, J. Bolden, T. Payne, P. Washington, and S. Williams. 2000. Palliative and end-of-life care in the African American community. *JAMA* 284(19):2518–2521.

Family Caregiver Alliance. 2015. *Selected long-term care statistics*. https://www.caregiver.org/selected-long-term-care-statistics (accessed April 24, 2018).

Favreault, M., and J. Dey. 2016. *Long-term services and supports for older Americans: Risks and financing research brief.* Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

Genworth Financial. 2016. *Genworth 2016 annual cost of care study: Costs continue to rise, particularly for services in home*. Richmond, VA: Genworth Financial.

Harris-Kojetin, L., M. Sengupta, E. Park-Lee, E. Valverde, C. Caffrey, V. Rome, and J. Lendon. 2016. Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013–2014. *Vital and Health Statistics* 3(38). https://www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf (accessed June 21, 2018).

Johnson, K. S. 2013. Racial and ethnic disparities in palliative care. *Journal of Palliative Medicine* 16(11):1329–1334.

Lichtenstein, R. L., K. H. Alcser, A. D. Corning, J. G. Bachman, and D. J. Doukas. 1997. Black/white differences in attitudes toward physician-assisted suicide. *Journal of the National Medical Association* 89(2):125–133.

Loggers, E. T., P. K. Maciejewski, E. Paulk, S. DeSanto-Madeya, M. Nilsson, K. Viswanath, A. A. Wright, T. A. Balboni, J. Temel, H. Stieglitz, S. Block, and H. G. Prigerson. 2009. Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology* 27(33):5559–5564.

Lynn, J. 2016. *Medicaring communities: Getting what we want and need in frail old age at an affordable cost*. Washington, DC: Altarum Institute.

Mack, J. W., M. E. Paulk, K. Viswanath, and H. G. Prigerson. 2010. Racial disparities in the outcomes of communication on medical care received near death. *Archives of Internal Medicine* 170(17):1533–1540.

Morrison, R. S., S. Wallenstein, D. K. Natale, R. S. Senzel, and L.-L. Huang. 2000. "We don't carry that"—failure of pharmacies in predominantly nonwhite neighborhoods to stock opioid analgesics. *New England Journal of Medicine* 342(14):1023–1026.

Morrissey, M. 2016. *The state of American retirement: How 401(k)s have failed most American workers.* Washington, DC: Economic Policy Institute.

Oregon Health Authority. 2017. *Oregon Death with Dignity Act 2017 data summary.* Salem: Oregon Health Authority.

Parikh, R. B., A. Montgomery, and J. Lynn. 2015. The Older Americans Act at 50—Community-based care in a value-driven era. *New England Journal of Medicine* 373(5):399–401.

Pennsylvania Health Care Association. n.d. *The need for long-term care continues to grow*. https://www.phca.org/for-consumers/research-data/long-term-and-post-acute-care-trends-and-statistics (accessed April 24, 2018).

Schmitz, J. E., M. Delrahim, J. H. Pickering, and A. M. Stoeppelwerth. 1997. Brief of the American Geriatrics Society as amicus curiae urging reversal of the judgments below: Vacco v. Quill. *Journal of the American Geriatrics Society* (45)4:491–499.

Tolle, S. W., V. R. Tilden, L. L. Drach, E. K. Fromme, N. A. Perrin, and K. Hedberg. 2004. Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide. *Journal of Clinical Ethics* 15(2):111–118.

Volandes, A. E., M. Paasche-Orlow, M. R. Gillick, E. F. Cook, S. Shaykevich, E. D. Abbo, and L. Lehmann. 2008. Health literacy not race predicts end-of-life care preferences. *Journal of Palliative Medicine* 11(5):754–762.

Wasserman, J., J. M. Clair, and F. J. Ritchey. 2016. Racial differences in attitudes toward euthanasia. *OMEGA–Journal of Death and Dying* 52(3):263–287.

Welch, L. C., J. M. Teno, and V. Mor. 2005. End-of-life care in black and white: Race matters for medical care of dying patients and their families. *Journal of the American Geriatrics Society* 53(7):1145–1153.

Williams, D. R., and R. Wyatt. 2015. Racial bias in health care and health: Challenges and opportunities. *JAMA* 314(6):555–556.

# 7

# Reflections on the Workshop and Evidentiary Gaps

In the workshop's final session, moderators of previous sessions were asked to summarize the themes that emerged from the 2 days of presentations and discussions. This chapter includes the themes as summarized by workshop session moderators as well as evidentiary gaps and potential directions for future discussion of physician-assisted death that were suggested by individual workshop participants. Summary statements made by session leaders do not imply consensus among workshop participants.

## SESSION ONE REFLECTIONS: EVIDENCE AND TERMS OF DISCUSSION

*Linda Ganzini*
*Professor of Psychiatry and Medicine*
*Oregon Health & Science University*

Linda Ganzini, who chaired the workshop's first session on evidence and terms of discussion, began by saying that she thought Daniel Sulmasy of Georgetown University had raised an interesting question, which concerned how one's beliefs affect the research questions one asks. Ganzini also recounted how Sulmasy pointed to the importance of keeping ethical ideas in mind when asking scientific questions about physician-assisted death. She said that one of the larger themes she heard was that even if it was possible to be assured about the motivations, competence, and mental status of every patient who asks for physician-assisted death, the

potential for acceptance of this practice may increase distrust among those in marginalized groups.

The challenge of assessing decision-making capacity, competence, and voluntariness were reccurring themes during the workshop, Ganzini said, adding that there are significant data and methods in the literature regarding determining decision-making capacity that could be applied in the context of physician-assisted death. This includes evaluating whether mental health professional are applying similar types of standards to bear on their evaluations of patients requesting physician-assisted death. Reflecting on Anthony Back's presentation, Ganzini commented that many of the patients who have been the first to avail themselves of these laws seem to celebrate the occasions of their deaths, and she asked whether these individuals might be changing society's ideas about death and how to die. She concluded her summary by reiterating the importance of research so as to avoid drawing conclusions based on information in the blogosphere.

## SESSION TWO REFLECTIONS: PROVIDER EXPERIENCES AND APPROACHES

*David Magnus*
*Thomas A. Raffin Professor of Medicine and Biomedical Ethics, Stanford University*
*Co-Chair, Stanford Hospital Ethics Committee*

*Neil Wenger*
*Professor of Medicine, University of California, Los Angeles (UCLA)*
*Director, UCLA Healthcare Ethics Center*
*Chair, UCLA Medical Center Ethics Committee*

David Magnus and Neil Wenger served as co-chairs of the session on provider experiences and approaches. Wenger observed that it might be possible to learn from what is essentially a natural experiment with nearly identical interventions being variably implemented in somewhat divergent populations. "How do we evaluate a paradigm shift that is an anathema to some and considered essential to others?" he asked. "This is a question that we should take to heart." He proposed that there could be a case-controlled trial comparing patients with terminal conditions who want aid-in-dying in three states that permit the practice and three that do not or in health care organizations that opt in and those that opt out. The difficulty, he acknowledged, would be in finding patients who want it, not necessarily patients who follow through. Such a study could also

evaluate the end-of-life care received by patients and its effect on families and clinicians.

For Wenger, physician-aided dying raises several questions that, he said, can create skepticism about current practices around which there formerly was no skepticism, such as: How certain are we about capacity and undue influence in withholding or withdrawing treatments that are common in hospitals today? Are there conflicts of interest regarding very aggressive treatment decisions that are decided between oncologists and patients or between surgeons and patients every day? What is the approach toward persons with disabilities? And, reflecting on the presentation by Joanne Lynn of the Altarum Institute, are we so comfortable focusing on the medical model of care because it is simply too painful to think about the social determinants of health and medical care?

The request for physician-assisted death is very powerful, Wenger said, and it stimulates a cascade of communication and intervention that appears to be missing in routine care but that should not be. He said that the resources devoted to preparing institutions to deal with requests for physician-assisted death far outweigh the number of patients affected, though these efforts may enable other necessary discussions about advance care planning and palliative care. Wenger also noted the importance of paying attention to the slippery slope discussed by several speakers.

Magnus commented that he had hoped this workshop would focus on the micro- and meso-level issues without as much focus on the macro-level moral and ethical issues, but this workshop has shown that to be impossible because all of these levels of discussion are intertwined in multiple ways. Though there are many questions, detailed below, that require research and data to answer, Magnus said that the data available are reassuring in some ways. However, he added, the fact that there is so much unknown about the practice of physician-assisted death in the United States is concerning, particularly regarding the ancillary effects on patient care. There is a potential, he said, that the availability of physician-assisted death and its use by a very small number of people will lead to a significant increase and improvement in high-quality end-of-life care in general. Alternatively, physician-assisted death may have negative ancillary effects on end-of-life care. Or, there may be no effects at all. It may turn out that physician-assisted death will only be relevant for a tiny number of people, in which case it will turn out to be a relatively unimportant topic. The bottom line is that research is needed to monitor these vastly different outcomes, Magnus said.

## SESSION THREE REFLECTIONS: PHYSICIAN-ASSISTED DEATH IN THE BROADER CONTEXT

*Joanne Lynn*
*Director, Center for Elder Care and Advanced Illness*
*Altarum Institute*

*Richard Payne*
*Esther T. Colliflower Professor of Medicine and Divinity (Emeritus),*
*Duke University*
*John B. Francis Chair, Center for Practical Bioethics*

*James Tulsky*
*Chair, Department of Psychosocial Oncology and Palliative Care,*
*Dana-Farber Cancer Institute*
*Professor of Medicine, Harvard Medical School*

James Tulsky remarked that the real focus of Session 3 ended up being how providers engage with and adapt to physician-assisted death when it becomes legal. He found this discussion useful, given that he lives in Massachusetts, where he expects physician-assisted death to become legal in 2020.

Tulsky's first of three take-home points from the session was that requests for physician-assisted death must stimulate deep conversation between clinicians and patients and enhance quality end-of-life care. The second was that context is important in that the implementation of a physician-assisted death program in a particular community cannot be separated from the ethnic and social make-up of that community. The third key point was that this issue is complicated for physicians and other health care providers. Moral distress, he said, is going to be present, and it is important to acknowledge and manage. Moral distress cannot be ignored, regardless of whether physician-assisted death is legal in a given jurisdiction.

It was clear from the presentations, Tulsky said, that creating an institutional policy requires massive stakeholder engagement and that patients must opt in rather than be offered these services by providers. It was also clear, Tulsky said, that in response to these new laws, health care systems have developed varied policies that focus as much on improving quality of end-of-life care as they do on allowing adherence to the laws. These policies all encourage the use of physician orders for life-sustaining treatment (POLST) forms and other measures to ensure that well-developed alternatives to physician-assisted death exist. Furthermore, each of these policies manages the requirement for secondary consultation differently, but generally uses this provision to improve the palliative care of

patients considering assisted dying. Several speakers made the point that systems that opt in need to provide some level of patient navigation and provisions for those providers who opt out. Tulsky said that it appears to be helpful to have a list of willing prescribers, but the question remains whether it is desirable or undesirable to have one or two "go-to" providers. Tulsky's final takeaway, he said, was that having willing health care providers present at the time of death can provide great comfort to patients and their families.

Richard Payne began his summary by noting his concern about the implications and impact that the widescale adoption of physician-assisted suicide will have on the profession of medicine, particularly in the context of the fragmented, disorderly way medicine is practiced in the United States. In particular, he said, he believes that such adoption may cause various issues for vulnerable, medically underserved minorities who have few long-term relationships with a health care provider. Reflecting on the different perspectives within various communities—in particular, African American communities and religious groups—Payne said he was surprised to learn that Archbishop Desmond Tutu recently voiced support for assisted death, reversing his lifelong position on the topic, in part due to observing the prolonged death of Nelson Mandela.[1] Payne stressed that no minority community is a monolith and said that there is a need for ethnographic data that crosses racial-ethnic strata as well as socioeconomic strata within a racial and ethnic group.

Payne said that voluntariness is the primary concern when considering vulnerable populations and physician-assisted death. He asked how slippery the slope will become and how voluntariness can remain protected as the processes around physician-assisted death are scaled up. Payne also challenged the workshop participants to have a subtler and more expansive view of the possible threats to the integrity of the voluntariness concepts. For instance, he said that the social determinants of health, living, and dying are critical and must be explored by hearing from the people most directly affected by the impact of key social factors on decisions about health care, including end-of-life care.

Lynn expressed concern that widespread adoption of physician-assisted death laws will trigger a very subtle but broad community-based discrimination against the elderly and people with disabilities, given the budgetary challenges regarding how the nation cares for those who are frail and elderly and who have disabilities. In her opinion, she said, the challenges facing older Americans should be a rallying cry for action that

[1] For more information, see https://www.npr.org/sections/parallels/2017/01/04/507294833/at-85-desmond-tutu-calls-for-the-right-to-an-assisted-death (accessed April 25, 2018).

goes far beyond concerns about physician-assisted death. Once the nation straightens out how it cares for older Americans and those with disabilities, she said, then physician-assisted death will become an intriguing question to address.

## SESSION FOUR REFLECTIONS: DATA COLLECTION IN THE UNITED STATES AND OTHER COUNTRIES

*Nancy Berlinger*
*Research Scholar*
*The Hastings Center*

Nancy Berlinger, who served as the chair of the session on data collection in the United States and other countries, remarked that Jennifer Gibson in her presentation said that data on access, quality, equity, and societal impacts would all be important indicators of the effect of physician-assisted death on the communities where it is legal. Gibson said that the perspectives of the public and patients are not always well captured by the reported data but are an important part of the story along with the perspectives of providers. One important question raised in the session was who has accountability for the collection and use of data on physician-assisted death. There was much discussion, Berlinger said, about what data the government in any country should collect, as well as which data public health officials are authorized to collect and analyze under the scope of legislation permitting physician-assisted death, and which data are beyond this scope but may be collected and analyzed by others. She remarked that communication about physician aid-in-dying was mentioned several times as something that would be hard to collect data on but which is fundamental to understanding the practice, including how patients may use the existence of a legal provision to initiate discussions about end-of-life care, whether or not they actually request a prescription.

Filling in gaps in understanding about how the physician-assisted death process works can compete directly with patient-centered goals that are seen as central to the process, she said. Examples would be trying to get patient accounts of their motivation for requesting physician-assisted death or getting in-depth patient and family experiences of the practice. Berlinger explained that patients and families undergoing the process of considering physician-assisted death or completing the process should not necessarily be expected to participate in research as it could create too heavy of a burden on what is essentially a private act.

Matthew Wynia raised a concern about how the medical community should develop and adhere to standards on physician-assisted death, including in jurisdictions where it is not yet or will never be legal, and how data collection should reflect those standards. Wynia proposed the idea of a national registry for information on physician-assisted death.

## DATA COLLECTION

Scott Kim, who acknowledged that he believes there is hardly a problem for which the answer is not "more data," said he found himself struggling with the call for more data in this space. He said that the data presented during the workshop did not address the question of whether physician-assisted death is a good thing, and that is typically the standard applied in health care. He noted that Wenger's suggestion for a case-controlled study would provide part of the answer, but that a better option might be to use the approach Oregon undertook when it randomized expanded access to Medicaid. Kim explained that the data collected on Medicaid use in Oregon through this approach has proven incredibly useful, and it is conceivable that one could take a similar approach in researching physician-assisted death.

Kim then raised a question for the workshop participants to consider: "If we are not going to make the social commitment to have that standard of data about physician-assisted death—and arguably, we ought not to—then would it be better for us to stop saying that this is a data-driven entity entirely, stop even calling for data, and just agree that this is something that is on that kind of uncomfortable saddle between the political and the metaphysical?"

Tulsky replied that he empathized with Kim's question because what has become clear to him over the course of the workshop was that no data will convince those who are firmly opposed to physician-assisted death to endorse the practice, nor will it convince the people who are firm advocates to oppose it. However, he said, he believes that data can provide insights into how to manage physician-assisted death, assuming it is going to be legal, so that it is done in a safe, efficacious, and effective manner with the best outcomes. Tulsky said that he did not want to make physician-assisted death a "data-free zone" but rather challenged workshop participants to be honest about what data can and cannot do as well as what the goals are of collecting those data. Magnus said that getting quality data about best practices in this area is important, and Anthony Back noted the importance of using research and data to effectively create a process of public and professional engagement on this issue.

## RESEARCH AND FURTHER DISCUSSIONS

Throughout the workshop, many participants spoke about gaps in the evidence concerning physician-assisted death and end-of-life care in general, as well as areas for further discussion regarding ethical and moral considerations surrounding physician-assisted death. In terms of empirical research, Lynn raised the question of who will fund research in this area. She noted that the mission of the National Institutes of Health concerns cures and the prevention of disease, but does not focus on researching how people will live. In her experience, a number of federal agencies and philanthropies are also uninterested in sponsoring research in this area. A research agenda has never been developed but nonetheless is needed, not least of all because end-of-life decisions are in most people's future, Lynn said.

Unanswered questions or potential opportunities for additional research mentioned by individual workshop participants during the workshop include the lists below. Some of the questions and issues listed below may have been raised by more than the one or more individuals attributed to each statement.

### Patient Care and Patient Choices

- What are the ancillary impacts of physician-assisted death laws on the care received by people who are not accessing the option and can the impact of physician-assisted death on clinical care beyond those who received the intervention be measured? (David Magnus, Neil Wenger)
- How has the legalization of physician-assisted death affected end-of-life care and palliative care for the people who are not going to take advantage of the law? (Barbara Koenig)
- If physician-assisted death leads to an activation of resources—time with providers, enhanced communication—with a positive impact for patients, can we better understand why this happens and export these lessons to contexts beyond physician-assisted death? (David Magnus)
- What is the consent process for palliative sedation if the drugs used for physician-assisted death do not work as planned and who is the responsible physician after the patient takes a lethal medication? (Timothy Quill)
- Can we better understand how physician-assisted death is similar to or different from suicide in other contexts? (Linda Ganzini)
- What are the financial, emotional, and other pressures being faced by older individuals using long-term services and supports, and

how do they affect considerations of physician-assisted death? (Joanne Lynn)
- Why has patient demand for medical aid-in-dying increased in recent years, and how should that increase inform the delivery of patient-directed care? (Kim Callinan)
- Do any patients complete physician-assisted death because their symptoms are not being managed? (Barbara Hansen)
- What are the rates of cognitive impairment and dementia in patients in home and community-based long-term care settings? (Cheryl Phillips)
- Are the legal safeguards regarding mental health screening failing to screen out some people with impaired judgment who should not be getting a prescription for lethal medication? (Thaddeus Pope)
- What is the frequency of complications arising during the procedure? (Matthew Wynia)

**Implementation**

- What harms occur because of the fracturing of continuity of care as a result of physicians or institutions opting out of physician-assisted death? (David Magnus)
- How do the prices of drugs used in physician-assisted death affect how people of different socioeconomic status make decisions regarding physician-assisted death? (Matthew Wynia)
- How is "terminal illness"—meaning a 6-month prognosis—currently being determined in jurisdictions where physician-assisted death is legal? (Scott Kim)
- How can we better understand the decisions physicians are making in terms of a patient's mental health and competence in the process of requesting physician-assisted death? (Tom Strouse)
- How strong a presumption of capacity is used, and what thresholds are applied in assessments of decision-making capacity? Are evaluators using a checklist to determine if a patient makes certain statements, or is there an in-depth clinical interview probing the person's understanding? Who provides the second opinion on these determinations? (Scott Kim)
- How often are patients referred to low-threshold physicians (e.g., physicians more likely to say yes rather than no to a request for physician-assisted death) and is this desirable or undesirable? (Scott Kim)
- What are the appropriate standards for evaluating capacity in the context of physician-assisted death, given that the current tools for evaluating capacity for other types of medical decision making are

based on the patient's ultimate goal being health, as opposed to death? (Tom Strouse)
- What is the effect of the waiting period and what constitutes an official request from a patient for physician-assisted death? What is the appropriate length of time to ensure that such a monumental decision consistently reflects the patient's wishes? (Barbara Koenig, Peter Reagan)
- What is the appropriate balance between legal safeguards and access to medical aid-in-dying? Which legal safeguards and regulatory requirements are necessary, and which ones create unnecessary delays and stigma? (Kim Callinan)
- What are best practices in provisions for safe disposal of unused drugs? (Matthew Wynia)
- What are the current practices in long-term care settings regarding physician-assisted death in locations where it is legal? (Joanne Lynn)

**Access and Utilization in Disabled and Vulnerable Populations**

- What are the views about physician-assisted death in the disabled community, and what is the use of physician-assisted death by disabled patients? Are there some disabled patients unable to access physician-assisted death who otherwise would choose that option? Are disabled patients getting access to physician-assisted death who otherwise would not be eligible? Is there evidence that physician-assisted death is having ancillary negative impacts on care for disabled patients? (David Magnus)
- What is the impact of physician-assisted death on vulnerable populations, particularly African American and other underserved minority communities and how do these communities feel about the practice of physician-assisted death? What will ethnographic research that crosses racial and ethnic strata as well as socioeconomic strata with a racial or ethnic group show about the acceptance of this practice and how legalization affects trust or mistrust in the health care system? (Jeffrey Berger, Barbara Koenig, Richard Payne)
- Is the lower use of physician-assisted death among low socioeconomic status groups reflective of unequal access, challenges in navigating the system, lack of information, or less of a preference for aid-in-dying among these groups? (Mara Buchbinder, Barbara Koenig)

- Does physician-assisted death pose a threat to voluntariness as it is scaled, particularly for vulnerable populations? What kinds of social determinants of health, living, and dying pose threats to the integrity of the voluntariness concept? (Richard Payne)
- What is the effect of physician-assisted suicide on individuals with psychiatric disorders? Does publicity about the practice trigger an increase in suicides? (Dan Sulmasy)
- What are the major challenges in accessing physician-assisted death in states where it is legal? (Kim Callinan, Omega Silva)

**Impact on Families, Clinicians, and Health Care Systems**

- Is there a difference in the grief process for survivors of a person who completed physician-assisted death compared to survivors of a person who died a "natural" death, who voluntarily stopped eating and drinking, or who committed suicide using a more violent means? (Barbara Hansen)
- What is the psychiatric effect of assisted suicide on families? (Dan Sulmasy)
- What are the psychological effects on clinicians of participating in assisted deaths? (Anthony Back)
- Does opting in contribute to more or less "burnout" among clinicians? (Barbara Hansen)
- What is the effect on institutions that opt in or opt out and to what extent do participating institutions believe they have an obligation to identify a provider if a patient's physician chooses not to participate, and how is this obligation carried out? (Barbara Hansen)
- What is the impact of not passing medical aid-in-dying laws? Does a lack of medical aid-in-dying laws create a more dangerous underground practice? (Kim Callinan)
- What mechanisms exist to support providers in carrying out physician-assisted death, and which practices and policies work best? (David Magnus)
- What is the impact on patients and families if their hospice program has a policy that does not allow their staff to be present in the home when the patient takes the medication? (Barbara Hansen)

**Ethical and Social Norms**

- What would serious, deliberative polling reveal about the impact of physician-assisted death on social and cultural norms? What can be done to implement genuine democratic public engagement on

physician-assisted death? (Barbara Koenig, Dan Sulmasy, Matthew Wynia)

- How are the various proposed expansions in laws outside of the United States likely to affect laws and regulations in this country? For example, what will be the positive and negative implications of expanding physician-assisted death to minors, of broadening or eliminating the terminal illness requirement, of modifying the self-administration requirement, or allowing physician-assisted death to be included in advance directives in other countries? (David Magnus)
- How do the conflicts of ethics and values for physicians, family members, and others involved in physician-assisted death affect those who need long-term services and supports? (Joanne Lynn)
- What are the potential and realized conflicts of ethics and values for providers of long-term care? (Joanne Lynn)
- How do societal processes, including how publics learn from each other directly or indirectly through mass and social media, affect the acceptance of physician-assisted death? How do those processes affect grieving process? (Nancy Berlinger)
- Can ethical frameworks be used to consider the impact that physician-assisted death may have in terms of a "gift exchange" between the patient and their loved ones, allowing them to confront and address death and dying? (Anthony Back)
- Is the public's interest in legalizing physician aid-in-dying part of a broader set of issues involving lack of trust in the health care system? (Barbara Koenig)
- How has long-term use of physician-assisted death in Oregon changed the nature of perceptions about this practice, and to what extent is it having an impact on moral dimensions of society? If there is a change in perceptions about this practice, is it occurring because of broader changes in society or because passing a law does produce profound changes in the ethos of a culture? (David Magnus, Neil Wenger)
- Separate from how providers adjust to physician-assisted death legalization, what will it take to develop a better understanding of where physician-assisted death sits in relation to a provider's own practice in terms of deciding how they will react to legalization? (Nancy Berlinger)
- Is there a psychological slippery slope in terms of how practitioners and patients begin to see physician-assisted death as part of normal practice and whether there is pressure to participate? (Daniel Sulmasy)

### Data Collection

- Additional research is needed on the validity of the legal reporting mechanisms in states where physician-assisted death is legal so as to better understand whether those data are true, as well as data on incidences of abuse. (Daniel Sulmasy)
- In states where physician-assisted death is legal, additional data are needed in order to assess how the laws are working. For instance, data are needed on the two types of slippery slope: (1) expansions of physician-assisted death within an accepted category of practice (e.g., "terminally ill") and (2) expansions in the categories of persons who can receive physician-assisted death (e.g., children, non-terminally ill, advance requests). (Scott Kim)

### Broader Research on End of Life

- What is the range and general practice of end-of-life alternatives to physician-assisted death—proportional palliative sedation, palliative sedation to unconsciousness, voluntarily stopping eating and drinking? How are these alternatives being used and what are the policies governing their use? (David Magnus, David Orentlicher)
- Can predictive models of when death is likely to occur help to operationalize the 6-month prognosis in a more precise manner? (Joanne Lynn)
- The desire to control how one dies is often dismissed as an illegitimate reason for physician-assisted death but is often a reflection of a patient's lifelong desire to overcome times of his or her life when controlled by others. Additional examination is needed of the range of end-of-life interventions and an individual's ability to leave this world in control. (Linda Ganzini)

# Appendix A

# Workshop Agenda

Physician-Assisted Death: Scanning the Landscape
and Potential Approaches: A Workshop

February 12–13, 2018

National Academy of Sciences Building
2101 Constitution Avenue, NW, Washington, DC

This National Academies of Sciences, Engineering, and Medicine workshop will explore the evidence base and research gaps relating to the implementation of the clinical practice of allowing terminally ill patients to access life-ending medications with the aid of a physician. The workshop is sponsored by The Greenwall Foundation. The workshop will examine what is known, and unknown, about how physician-assisted death is practiced and accessed in the United States; it will not be a focus of the workshop to discuss at length the moral or ethical arguments for or against the practice of physician-assisted death. The workshop will serve as a neutral space to facilitate dialogue in order to help inform ongoing discussions between patients, their providers, and other health care stakeholders.

## STATEMENT OF TASK

- What is known empirically about the access to and practice of physician-assisted death in the United States and in other countries?
  - In states where it is legal:
    - What is known about who accesses it and the impact the practice has on the patient and family experience of death?
    - What is known about whether legal safeguards are observed?
    - What is known about whether concerns about vulnerable populations have been realized when it is practiced?
  - In states where it is not legal:
    - What is known about the current practice of physician-assisted death and what patients are accessing it?
    - Is its practice accompanied by safeguards, if any, and how do such safeguards compare with safeguards enacted in states where it is legalized?
  - What are the gaps in empirical data about the practice of physician-assisted death in the United States?
    - How do the data collected in the United States compare with the data collection in countries like the Netherlands, which have more extensive reporting and data collection?
- What are potential approaches for physicians:
  - Who practice in a state where it is legal but are personally opposed to physician-assisted death.
  - Who receive a request for access but the situation does not adhere to the applicable state's legal framework.
  - Who receive a request for access when the practice is legal in nearby states but not in the state of practice.
- What is known about how palliative care and hospice services have incorporated the practice of physician-assisted death in states where it is legal?

## DAY 1: February 12
## Lecture Room

**OPENING REMARKS** **9:00–9:10 a.m.**

Welcome and Introductory Remarks
***Jim Childress***, University of Virginia (*Workshop Chair*)

**Session I: WHAT DO WE KNOW?: THE EVIDENCE AND TERMS OF DISCUSSION** **9:10 a.m.–1:00 p.m.**

*Session Objectives:*

- Discuss an overview of the evidentiary landscape.
  - What is known about current practice? What are the limitations of current evidence about practices?
  - Is the evidence base adequate to inform ethical debates about the practice? Which ethical arguments about physician-assisted death could be examined and informed by scientific evidence, and which cannot?
- Discuss an overview of the regulatory landscape: Where is this legal, what is legal, and what may be on the horizon?
- Highlight terminology, including gaps or ambiguity in key definitions.

**Session Chair:** ***Linda Ganzini***

9:10 a.m. **Interview—A Patient and Family Perspective**
- ***Dan Diaz***, Brittany Maynard's husband; Latino Leadership Council, Compassion & Choices
  *Interviewed by* ***Anthony Back***, Professor of Medicine, University of Washington

9:30 a.m. **Colloquy—Evidentiary Landscape**
- ***Linda Ganzini***, Professor of Psychiatry and Medicine, Oregon Health & Science University
- ***Anthony Back***, Professor of Medicine, University of Washington
- ***Dan Sulmasy***, André Hellegers Professor of Biomedical Ethics, Kennedy Institute of Ethics, Departments of Philosophy and Medicine, Georgetown University

10:30 a.m. ***Discussion with workshop participants moderated by Linda Ganzini***

10:45 a.m. **Break**

11:00 a.m. **Legal and Conceptual Frameworks**

**Legal/Regulatory Landscape**
- ***David Orentlicher***, Co-Director, University of Nevada, Las Vegas, Health Law Program, and the Cobeaga Law Firm Professor of Law, University of Nevada, Las Vegas

**Terminal Illness: Operationalizing the Definition**
- ***Joanne Lynn***, Director, Center for Elder Care and Advanced Illness, Altarum Institute

**Key Terms and Taxonomy**
- ***Scott Kim***, Senior Investigator, Department of Bioethics, National Institutes of Health Clinical Center
- ***Tom Strouse***, Medical Director, Stewart and Lynda Resnick Neuropsychiatric Hospital, University of California, Los Angeles

***Respondent***
- ***John Keown***, Rose F. Kennedy Professor of Christian Ethics, Kennedy Institute of Ethics, Georgetown University

12:30 p.m. ***Discussion with workshop participants moderated by Linda Ganzini***

1:00 p.m. **LUNCH**

**Session II: PROVIDER EXPERIENCES AND APPROACHES** **1:30–5:00 p.m.**

*Session Objectives:*

- Outline current provider practices when a request is made. Discuss the experiences and approaches of health care providers across different jurisdictions.
- Outline the statutory safeguard requirements and implications of them—how they are implemented and experienced. Discuss potential approaches for different case scenarios: cases that do not fit the applicable legal definitions; cases in jurisdictions where the practice is not legal; and cases in jurisdictions where the practice is legal but has been refused by a provider.

**Session Co-Chairs:** ***David Magnus*** **and** ***Neil Wenger***

1:30 p.m. **Panel #1: Current Landscape: Implementation and Practice**

***Panel Moderator: David Magnus***, Stanford University

**Presentations:**

- ***Thaddeus Pope***, Director, Health Law Institute and Professor of Law, Mitchell Hamline School of Law, Minnesota
- ***Courtney Campbell***, Hundere Professor of Religion and Culture, Oregon State University School of History, Philosophy, and Religion
- ***Frances Norwood***, Assistant Research Professor in Anthropology, George Washington University
- ***Helene Starks***, Associate Professor, Department of Bioethics and Humanities, University of Washington School of Medicine
- ***Anita Silvers***, Professor and Associate Chair, San Francisco State University Department of Philosophy
- ***John Kelly***, New England Regional Director, Not Dead Yet; Director, Second Thoughts

2:45 p.m. ***Discussion with workshop participants moderated by David Magnus***

3:15 p.m. **Break**

3:30 p.m. **Panel #2*:* Potential Approaches for Handling Requests**

***Panel Moderator: Neil Wenger***, University of California, Los Angeles

**Presentations:**

- ***Peter Reagan***, family physician, Oregon
- ***Erik Fromme***, Director, Serious Illness Care Program, Ariadne Labs, Dana-Farber Cancer Institute
- ***Timothy Quill***, Professor of Medicine, Psychiatry, Medical Humanities and Nursing, Palliative Care Division, University of Rochester School of Medicine
- ***Mara Buchbinder***, Associate Professor of Social Medicine, University of North Carolina at Chapel Hill School of Medicine

- ***Barbara Koenig***, Professor, Institute for Health and Aging and Department of Anthropology, History, and Social Medicine and Director, University of California, San Francisco (UCSF), Bioethics, UCSF School of Medicine

4:30 p.m. ***Discussion with workshop participants moderated by Neil Wenger***

5:00 p.m. Adjourn Day 1

**DAY 2: February 13**
**Lecture Room**

**OPENING REMARKS** **9:00–9:10 a.m.**

Recap Day One and Discussion with Workshop Participants
***Jim Childress***, University of Virginia (*Workshop Chair*)

**Session III: PHYSICIAN-ASSISTED DEATH IN THE BROADER CONTEXT** **9:10–10:50 a.m.**

*Session Objectives:*

- Discuss what is known about how palliative care and hospice have incorporated the practice of physician-assisted death in states where it is legal.
- Discuss perspectives and practices of long-term care provider systems.

**Session Co-Chairs: *James Tulsky, Richard Payne*, and *Joanne Lynn***

9:10 a.m. **Palliative Care and Hospice**

***Panel Moderator: James Tulsky***, Dana-Farber Cancer Institute

**Presentations:**
- ***Stephanie Harman***, Clinical Associate Professor, Medicine, Stanford University; Medical Director, Palliative Care, Stanford Health Care
- ***Gary Pasternak***, Medical Director, Mission Hospice

- ***Jeffrey Berger***, Chief of the Division of Palliative Medicine and Director of Clinical Ethics, New York University Winthrop Hospital
- ***Steve Pantilat***, Kates-Burnard and Hellman Distinguished Professor in Palliative Care, UCSF; Director, UCSF Palliative Care Program

9:50 a.m. ***Discussion with workshop participants moderated by James Tulsky***

10:05 a.m. **Long-Term Services and Supports**

***Panel Moderator: Richard Payne***, Duke University

**Presentations:**
- ***Joanne Lynn***, Director, Center for Elder Care and Advanced Illness, Altarum Institute
- ***Cheryl Phillips***, President and Chief Executive Officer, SNP Alliance
- ***Barb Hansen***, Chief Executive Officer, Oregon Hospice and Palliative Care Association

10:35 a.m. ***Discussion with workshop participants moderated by Richard Payne***

10:50 a.m. **Break**

**Session IV: DATA COLLECTION IN THE UNITED STATES AND OTHER COUNTRIES** **11:00 a.m.–12:15 p.m.**

*Session Objective:*

- Consider what we can learn from other countries, focusing on how data collected in the United States compare with the data collection in other countries with legal aid-in-dying frameworks.

**Session Chair:** ***Nancy Berlinger***, The Hastings Center

11:00 a.m. **Data Collection in the United States and Other Countries**

- ***Katrina Hedberg***, Health Officer and State Epidemiologist, Oregon
- ***Bregje Onwuteaka-Philipsen***, Amsterdam Public Health Research Institute
- ***Jennifer Gibson***, Director, University of Toronto Joint Centre for Bioethics
- ***Matthew Wynia***, Director of the Center for Bioethics and Humanities, University of Colorado Anschutz Medical Campus

11:50 a.m. ***Discussion with workshop participants moderated by Nancy Berlinger***

12:15 p.m. **LUNCH**

**Session V: OBSERVATIONS FROM THE WORKSHOP AND POTENTIAL NEXT STEPS FOR THE FIELD 1:00–3:00 p.m.**

*Session Objectives:*

- Reflect on key takeaways from the panel presentations and discussions.
- Highlight evidentiary gaps that, if filled, would help inform potential approaches for health care providers, and discuss potential approaches to address identified evidentiary gaps.
- Explore what is next in the conversation—including potential related issues that remain undeveloped but linger on the horizon.

**Session Chair:** ***Jim Childress***

1:00 p.m. **Observations from the Workshop**

***Panel Moderator: Scott Halpern***, University of Pennsylvania

- ***Omega Silva***, Professor Emeritus of Medicine, George Washington University
- ***Kim Callinan***, Chief Executive Officer, Compassion & Choices
- ***Daniel Callahan***, Co-Founder, President Emeritus, The Hastings Center

1:30 p.m. ***Discussion with workshop participants moderated by Scott Halpern***

1:45 p.m. **Reflections on the Evidentiary Gaps and Key Takeaways from the Workshop**

***Panel Moderator: Jim Childress***

- ***Linda Ganzini***, Session I: What Do We Know?/The Evidence and Terms of Discussion
- ***David Magnus and Neil Wenger***, Session II: Provider Experiences and Approaches
- ***Joanne Lynn, Richard Payne, and James Tulsky***, Session III: Physician-Assisted Death in the Broader Context
- ***Nancy Berlinger***, Session IV: Data Collection in the United States and Other Countries

2:30 p.m. ***Discussion with workshop participants moderated by Jim Childress***

3:00 p.m. **WORKSHOP ADJOURNS**

# Appendix B

# Biographical Sketches of Workshop Speakers and Planning Committee Members

**Anthony Back, M.D.,** is a professor of medicine at the University of Washington, Division of Oncology, and the co-founder of VitalTalk. He is the co-director of the Cambia Palliative Care Center of Excellence with Dr. Randy Curtis. His research on patient–physician communication has been funded by the National Cancer Institute, Robert Wood Johnson Foundation, Gordon and Betty Moore Foundation, Arnold P. Gold Foundation, and many others. He was a faculty scholar for the Project on Death in America. He co-founded VitalTalk as a 501(c)(3) foundation with Dr. Robert Arnold and Dr. James Tulsky to use a start-up entrepreneurship approach to disseminating clinician-skills training for serious illness. Currently he is the principal investigator for Care.Lab, a national initiative funded by the John A. Hartford Foundation, to scale up innovations that improve care for serious illness. His research in physician-assisted dying dates back to 1996, before the Washington Death with Dignity legislation was passed, when he published a survey showing that 12 percent of physicians in Washington State had received an explicit request for physician-assisted suicide in the past year, and that the most common underlying reasons for these requests were non-physical—loss of control, being a burden, being dependent on others, and loss of dignity. Follow-up studies showed that physicians lacked expertise in communicating about patients' fears in the dying process, and that many patients used physician-assisted dying as a gateway to a conversation about dying. He recently provided consultation to a consortium of Nordic countries considering legalization of physician-assisted dying practices. In his practice

as an oncologist in Washington State, he has been involved in many discussions with patients and families about these issues.

**Jeffrey T. Berger, M.D., FACP,** is the chief of the Division of Palliative Medicine and Bioethics at the New York University Winthrop Hospital and a professor of medicine at Stony Brook University School of Medicine. Dr. Berger currently chairs the Committee on Bioethical Issues of the Medical Society of the State of New York and is a member of the New York State Palliative Care Education and Training Council. He recently served as the chairman of the ethics committee of the American Academy of Hospice and Palliative Medicine, has served on the American College of Physicians' Committee on Ethics, Professionalism, and Human Rights, and on the Clinical Ethics Consultation Affairs Committee of the American Society for Bioethics and Humanities. Dr. Berger is an associate editor of *The Journal of Clinical Ethics* and has published widely in the medical and bioethics literature. His particular interests are in surrogate decision making and end-of-life ethics.

**Nancy Berlinger, Ph.D.,** is a research scholar at The Hastings Center, an independent, nonpartisan, nonprofit bioethics research institute based in Garrison, New York. She oversees the center's program area on aging, chronic conditions, and the end of life. Her research interests include societal challenges arising from population aging. She co-directs a 2-year grant-funded planning process to develop a social ethics framework for bioethics scholarship in this area. Products will include an essay set to be published in early 2019. She directed the multiyear research and consensus project to revise the landmark *Hastings Center Guidelines* on treatment decision making and care near the end of life and was the first author of the new edition (Oxford University Press, 2013). Her collaborations with the Society of Hospital Medicine and the American Association of Critical-Care Nurses to translate ethics guidelines into practice have developed a primary palliative care communication process for frontline clinicians caring for seriously ill patients (2017). With colleagues at the National University of Singapore (NUS), the Ethox Centre of Oxford University, and The Hastings Center, she co-developed and co-edited the *Singapore Bioethics Casebook*, an online public tool for learning about treatment decision making (NUS, 2014) and ethical challenges in aging societies (NUS, 2017). She co-founded and co-directs The Hastings Center's Undocumented Patients project, which maintains a Web-based knowledge hub used by clinicians, scholars, students, journalists, and policy makers and has developed policy recommendations for improved city-level solutions. Her books on problems of safety and harm in health care systems include *After Harm: Medical Error and the Ethics of Forgiveness* (Johns Hopkins

University Press, 2005) and *Are Workarounds Ethical?: Managing Moral Problems in Health Care Systems* (Oxford University Press, 2016). She is a member of the Bioethics Committee at Montefiore Medical Center and an adjunct lecturer at Lehman College, City University of New York, both in the Bronx, New York.

**Mara Buchbinder, Ph.D.,** is an associate professor of social medicine and adjunct associate professor of anthropology at the University of North Carolina (UNC) at Chapel Hill, as well as core faculty in the UNC Center for Bioethics. Dr. Buchbinder is a medical anthropologist with broad interests in cultures of health, illness, and medicine in the United States. Her recent work focuses on how patients, families, and health care providers navigate social and ethical challenges resulting from changes in medical technology, law, and health policy. Her current project, the Vermont Study of Aid-in-Dying, is an ethnographic study of the implementation and cultural impact of Vermont's Patient Choice and Control at End of Life Act. Dr. Buchbinder is the recipient of a Greenwall Faculty Scholars Award (2015–2017) and a 2017 Phillip and Ruth Hettleman Prize for Artistic and Scholarly Achievement by Young Faculty at UNC at Chapel Hill. Her research has been funded by the National Institutes of Health, the National Science Foundation, The Greenwall Foundation, and the Wenner-Gren Foundation.

**Daniel Callahan** is a pioneer in bioethics, a noted author, and one of the world's preeminent bioethics scholars. He co-founded The Hastings Center with Willard Gaylin in 1969 and served as its director from 1969 to 1983 and president from 1984 to 1996. He is currently a member of its board of directors. He is a senior scholar at the Institute of Politics and Policy Studies at Yale University and has been a senior lecturer at Harvard Medical School. He is also a cofounder of the Yale–Hastings Program in Ethics and Health Policy. Dr. Callahan received his Ph.D. in philosophy from Harvard and his B.A. from Yale. He has honorary degrees from several universities, including Charles University in the Czech Republic. He is an elected member of the National Academy of Medicine and a member of the National Academy of Social Science, and he is a former member of the director's advisory committee of the Centers for Disease Control and Prevention and of the advisory council of the U.S. Department of Health and Human Services Office of Scientific Integrity. He won the 1996 Freedom and Scientific Responsibility Award of the American Association for the Advancement of Science. He was awarded the 2008 Centennial Medal of the Harvard Graduate School of Arts and Sciences. Dr. Callahan is the author or editor of 47 books and 450 articles. His most recent books are *The Five Horsemen of The Modern World: Climate, Food, Water, Chronic*

*Illness, and Obesity* (Columbia University Press, 2016); *In Search of the Good: A Life in Bioethics* (MIT Press, 2012); *The Roots of Bioethics: Health, Progress, Technology, Death* (Oxford University Press, 2012); and *Taming the Beloved Beast: How Medical Technology Costs Are Destroying Our Health Care System* (Princeton University Press, 2009). He has contributed articles to *The New York Times*, the *New England Journal of Medicine*, the *Journal of the American Medical Association*, *The New Republic*, *Deadalus*, and *The Atlantic*.

**Courtney S. Campbell, Ph.D.,** is the Hundere Professor of Religion and Culture at Oregon State University in Corvallis. He has been a member of the Oregon Hospice Association Ethics Task Force on Physician Aid in Dying and the National Hospice and Palliative Care Organization Ethics Task Force on Physician-Assisted Death. He has published several articles and essays on the impact of legalized physician-assisted death in Oregon and Washington for hospice programs as well as more general writings on end-of-life ethics.

**James Childress, Ph.D.,** is a philosopher and theologian whose scholarship addresses ethics, particularly biomedical ethics. Currently he is the John Allen Hollingsworth Professor of Ethics at the Department of Religious Studies at the University of Virginia (UVA) and he teaches public policy at the Frank Batten School of Leadership and Public Policy. He is also professor of medical education at UVA and directs its Institute for Practical Ethics and Public Life. He holds a B.A. from Guilford College, a B.D. from Yale Divinity School, and an M.A. and a Ph.D. from Yale University. He was vice-chairman of the U.S. Task Force on Organ Transplantation, and he has also served on the board of directors of the United Network for Organ Sharing (UNOS), the UNOS Ethics Committee, the Recombinant DNA Advisory Committee, the Human Gene Therapy Subcommittee, the Biomedical Ethics Advisory Committee, and several data and safety monitoring boards for National Institutes of Health clinical trials. From 1996 to 2001 he served on the presidentially appointed National Bioethics Advisory Commission. He is a fellow of The Hastings Center, an independent bioethics research institution.

**Dan Diaz** is an advocate for end-of-life options. He was the husband of Brittany Maynard, the 29-year-old woman who died in November 2014 from a brain tumor. The couple moved from California to Oregon, one of seven states that has authorized medical aid-in-dying, in order for Brittany to have the option of a gentle dying process. As a result of Brittany's story, legislators have introduced bills to authorize medical aid-in-dying in more than 25 states. Mr. Diaz advocates for expanding the availability of end-of-life options for terminally ill individuals. His efforts

were instrumental in securing the passage of the legislation in California, Colorado, and the District of Columbia. His efforts continue across the country, keeping the promise he made to Brittany.

**Erik Fromme, M.D., M.C.R.,** is the director of the Serious Illness Care Program at Ariadne Labs. As director, he oversees the research, growth, and spread of the program. Prior to joining Ariadne, Dr. Fromme was the section chief and medical director for palliative care at Oregon Health & Science University, founding its outpatient palliative care program and developing a research program in patient-reported outcomes, hospice and palliative care health service research, and physician orders for life-sustaining treatment.

**Linda Ganzini, M.D., M.P.H.,** is the associate director of the Health Services Research and Development Center of Innovation in the Veterans Affairs (VA) Portland Health Care System. Dr. Ganzini joined the Oregon Health & Science University (OHSU) Department of Psychiatry faculty immediately upon completion of a gerontology fellowship at the Portland VA Medical Center (PVAMC) in 1989. She also joined the psychiatry staff at the Portland VA as the director of the Consult Liaison Psychiatry Service (1989–1998, 2015–present). From 1994 to 1997, she was the director of the OHSU Medical Student Clerkship in Psychiatry, and from 1996 to 2001, she was the associate director of the OHSU Psychiatry Residency Training Program. The department honored her with the Psychiatry Residency Teaching Award in 1991 and the Distinguished Service Award in 1996 in recognition of her contributions to the residency training program. She was awarded the Nancy C. A. Roeske, M.D., Certificate of Recognition for Excellence in Medical Student Education by the American Psychiatric Association in 1997 and the Faculty Development Award in 2003. She was the director of the Health Services Research and Development Enhancement Award Program at the PVAMC between 2006 and 2013. Dr. Ganzini's research interests are centered in the areas of geriatric mental health, end-of-life care issues, and suicide. Dr. Ganzini has published extensively in peer-reviewed journals, invited articles, book chapters, editorials, and commentaries on the topics of Oregon's Death with Dignity Act, physician aid-in-dying, assessing mental health in the terminally ill, and medical ethics among psychiatrists and health care providers.

**Jennifer Gibson, Ph.D.,** is the Sun Life Financial Chair in Bioethics and director of the University of Toronto Joint Centre for Bioethics; an associate professor in the Institute of Health Policy, Management & Evaluation and the Dalla Lana School of Public Health; and the director of the World Health Organization Collaborating Centre for Bioethics at the University

of Toronto. Dr. Gibson has a Ph.D. in philosophy (bioethics and political theory). Her program of research and teaching focuses on ethical issues at the level of health systems and institutions. She is particularly interested in the role and interaction of values in decision making at different levels in the health system and in developing evidence-informed and ethically grounded approaches to today's wicked health problems, such as resource allocation, infectious disease outbreaks, complex chronic disease, and health equity locally and globally. Dr. Gibson has served on government and policy advisory committees related to Ebola preparedness and response, critical care triage, drug funding and supply, organ transplantation, pandemic planning, public health surveillance, and health system integration. Internationally, Dr. Gibson works closely with the World Health Organization and the Global Network of Collaborating Centres for Bioethics on global health ethics issues. Nationally, in 2015–2016, she chaired the Provincial–Territorial Expert Advisory Group on Physician-Assisted Death and was an expert witness to the Canadian Parliament on Bill C-14, which is Canada's federal legislation on medical assistance in dying (MAiD). She is a member and working group chair of the Canadian Council of Academies' Expert Panel on MAiD, which was created at the request of the government of Canada to conduct three independent studies of medical assistance in dying in relation to mature minors, advance requests, and mental illness as a sole underlying medical condition. She is also working with various governance levels on data collection and monitoring of MAiD.

**Scott Halpern, M.D., Ph.D.,** is an associate professor of medicine, epidemiology, and medical ethics and health policy at the University of Pennsylvania Perelman School of Medicine, and a practicing critical care medicine doctor. He is the founding director of the Palliative and Advanced Illness Research Center, which generates evidence to advance policies and practices that improve the lives of all people affected by serious illness. He is also the founding director of the Fostering Improvement in End-of-Life Decision Science program, the nation's only program that applies behavioral economic principles to understand and improve upon the health decisions made by seriously ill patients, their caregivers, and their clinicians. Among his nearly 20 awards are The Greenwall Foundation Faculty Scholar Award in Bioethics, AcademyHealth's Alice S. Hersh New Investigator Award, the Young Leader Award from the Robert Wood Johnson Foundation, the American Federation for Medical Research's Outstanding Investigator Award for the best scientist in any field under the age of 45, and the Association for Clinical and Translational Science's Distinguished Investigator Award for lifetime achievement in translation of clinical practice into public benefit and policy. He is an elected member

of the American Society of Clinical Investigation, a member of the editorial boards of the *Annals of Internal Medicine* and the *American Journal of Bioethics*, and from 2013 to 2015 he was an Anniversary Fellow at the Institute of Medicine. Dr. Halpern has authored more than 150 peer-reviewed articles, and this work has been featured in every major media outlet.

**Barbara Hansen, R.N.,** is the chief executive officer of the Oregon Hospice and Palliative Care Association. She is an R.N. with more than 30 years of experience in hospice and home care in Oregon. She has been a hospice nurse case manager, clinical coordinator, and program director. She has also provided direct patient care as a wound and ostomy nurse and has visited home care and hospice programs in more than 30 states as a Joint Commission surveyor. She is passionate about improving access to home-based palliative care services.

**Stephanie Harman, M.D.,** is a clinical associate professor in the Stanford University School of Medicine's Department of Medicine and a recognized expert in palliative care, bioethics, and health care communication skills. She is currently the clinical section chief of palliative care in the Division of Primary Care and Population Health. She is the founding medical director of the adult palliative care program and co-chair of the ethics committee at Stanford Health Care, and she co-authored Stanford's policy on participation in California's End of Life Option Act. She served as a steering committee member and a panelist for the End of Life Option Act 2017 Main Convening of California Stakeholders Conference. She is an awardee of the 2017 Cambia Health Foundation's Sojourns Scholar Leader program, a career award program for emerging palliative care leaders. Prior to that she completed a professorship grant from the Gold Foundation to teach humanistic communication, and she is a faculty member of the Academy of Communication in Healthcare. Her current projects include decision making for admissions to the intensive care unit and the application of machine learning and predictive informatics to improve palliative care access.

**Katrina Hedberg, M.D., M.P.H.,** is the health officer and state epidemiologist with the Public Health Division of the Oregon Health Authority. Dr. Hedberg has worked at the Oregon Public Health Division for the past 25 years as a public health physician and manager in a variety of programs. She is also an affiliate professor in the Oregon Health & Science University–Portland State University School of Public Health. Dr. Hedberg received her undergraduate degree from Yale University and her medical degree from Oregon Health & Science University. She completed 1 year of clinical training at Emory University and then worked

for the Centers for Disease Control and Prevention from 1986 to 1989. Dr. Hedberg earned her master's of public health degree from the University of Washington and is board certified in public health and preventive medicine. Dr. Hedberg has co-authored numerous publications, including articles on nontuberculous mycobacterial disease, a community-wide outbreak of cryptosporidiosis, smoking-related mortality, and Oregonians' participation in the Death with Dignity Act. Her recent projects include evaluating the public health impact of marijuana legalization, and convening a task force to develop statewide prescribing guidelines to address the epidemic of opioid overdose and misuse in Oregon.

**Barbara Jones, Ph.D., M.S.W., FNAP,** is the associate dean for health affairs and University Distinguished Teaching Professor at The University of Texas (UT) at Austin Steve Hicks School of Social Work and the co-director of the Institute for Collaborative Health Research and Practice. She is the associate director of social sciences and community-based research at the LIVESTRONG Cancer Institutes and a professor of population health, psychiatry, and oncology at Dell Medical School. Dr. Jones's research focuses on improving care for children, adolescents, and young adults with cancer and their families. She teaches courses across the curriculum on topics such as grief and loss, social work in health care, psychosocial oncology, and interprofessional education. Dr. Jones's clinical experience has been primarily in the fields of pediatric oncology, children's grief and loss, pediatric palliative and end-of-life care, adolescent and young adult oncology, grief, trauma, and survival. Her current research focuses on coordinated care for children facing illness, family resilience, pediatric palliative care, pediatric oncology social work interventions, and adolescent and young adult cancer survivors. Dr. Jones has received national awards for her work in oncology and palliative care, including the 2014 American Psychosocial Oncology Society Outstanding Training and Education Award, the 2013 Social Worker of the Year from the Association of Pediatric Oncology Social Workers, and the 2009 Project on Death in America Social Work Leadership Award. She has also received awards for her teaching, such as the 2014 UT Dads' Centennial Teaching Fellowship Award, and in 2016 she was selected as a member of UT's Academy of Distinguished Teachers.

**John Kelly, M.A.,** is a long-time, Boston-based disability rights activist and writer. He is the New England regional director for Not Dead Yet, the national grassroots disability group opposed to legalizing assisted suicide. Since 2011 he has also been the director of Second Thoughts MA: Disability Rights Advocates Against Assisted Suicide. Mr. Kelly has been writing, testifying, and speaking out against the legalization of assisted

suicide for 20 years. Mr. Kelly has appeared on CNN and Fox News, and in *The Boston Globe*, Newark *Star-Ledger*, and many others. As someone commonly referred to as "paralyzed from the neck down" from a spinal cord injury, Mr. Kelly refutes the commonplace idea that people in his condition would be "better off dead," as seen in myriad films from *Whose Life Is It Anyway* to *Million Dollar Baby* and last year's hit *Me Before You*. He finds that the same prejudice animates much of the "right to die" movement, which translates disability into a poor "quality of life" judgment that pushes severely disabled people, including people disabled by their serious illness, toward death. During the assisted suicide ballot campaign in 2012, Mr. Kelly represented the disability rights perspective, thrice squaring off against assisted suicide proponent Dr. Marcia Angell. Other opposition groups often asked Mr. Kelly to represent them at public events. He has a master's in sociology from Brandeis and is A.B.D. in its Ph.D. program. He has presented at academic conferences throughout the country. His most recent publication is an op-ed in *The Boston Globe* on January 16, 2018. It can be found at https://www.bostonglobe.com/opinion/2018/01/16/the-mass-legislature-must-say-assisted-suicide/oPzo9UYRWbf7jJMGfC9dxJ/story.html (accessed June 21, 2018).

**John Keown, D.C.L. (Oxon.),** holds the Rose Kennedy Chair in the Kennedy Institute of Ethics at Georgetown University. Formerly he taught the law and ethics of medicine in the Faculty of Law at the University of Cambridge. His books include *Euthanasia Examined* (Cambridge University Press, 1995); *Euthanasia, Ethics and Public Policy* (Cambridge University Press, 2002, 2nd edition forthcoming 2018); *Debating Euthanasia* (with Emily Jackson; Hart, 2012); *The Law and Ethics of Medicine* (Oxford University Press, 2012); and *Bioethics and the Human Goods* (with Alfonso Gómez-Lobo; Georgetown University Press, 2015). His research on euthanasia has been cited by the Law Lords and by the U.S. Supreme Court.

**Scott Kim, M.D., Ph.D.,** is a senior investigator in the Department of Bioethics at the National Institutes of Health. Dr. Kim received his M.D. from Harvard and a Ph.D. in moral philosophy (on Kantian ethics) from the University of Chicago, and he trained in adult psychiatry at the Massachusetts General Hospital. Dr. Kim combines philosophical, clinical, and empirical research approaches to address a variety of ethical issues (ethical issues in pragmatic clinical trials, assessment of decision-making capacity, surrogate consent for incapacitated patients, theory and practice of informed consent, and physician-assisted death). He is especially interested in the interface between psychiatry and euthanasia/assisted suicide as the practice is actually implemented in Belgium and the Netherlands, and its implications for the United States and Canada. Dr. Kim's work has

been supported by the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, the National Institute on Aging, the National Human Genome Research Institute, the Michael J. Fox Foundation, the American Association for Geriatric Psychiatry, and The Greenwall Foundation. His work has appeared in the *New England Journal of Medicine*, *Nature*, *JAMA*, and other key journals. His book *Evaluation of Capacity to Consent to Treatment and Research* (Oxford University Press, 2010) was recently translated into Japanese. He currently serves on the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. More information can be found at scottkimbioethics.org (accessed June 21, 2018).

**Barbara A. Koenig, Ph.D.,** is a professor of bioethics and medical anthropology, based at the Institute for Health and Aging at the University of California, San Francisco (UCSF). She is the director of UCSF Bioethics, a nascent program that spans ethics research, clinical ethics, and ethics education across the university's four professional schools. Professor Koenig pioneered the use of empirical methods in the study of ethical questions in science, medicine, and health. She has longstanding interests in palliative care and technology use near the end of life. In San Francisco in the early 1980s, she was one of the first anthropologists to work on the then-emerging epidemic of HIV/AIDS, focusing on the impact of the disease on clinicians' care for dying patients. Professor Koenig also led the first National Institutes of Health–funded study of the dynamics of end-of-life decision making and patient choice in a public hospital cancer clinic serving patients from varied ethnocultural backgrounds; her work revealed the limitations of traditional bioethics practices in a diverse society. Professor Koenig's research led to her being named a Soros Faculty Scholar in the Open Society Institute's Project on Death in America. With the recent passage of California's physician aid-in-dying legislation, she convened a statewide conference to bring together the law's opponents and proponents to reflect on implementation challenges.

**Joanne Lynn, M.D., M.S.,** is the director of the Center for Elder Care and Advanced Illness at the Altarum Institute. She is a geriatrician, hospice physician, health services researcher, quality improvement advisor, and policy advocate who has focused on shaping American health care so that every person can count on living comfortably and meaningfully through the period of serious illness and disability in the last years of life, at a sustainable cost to the community. She now leads Altarum's work on elder care and advanced illness. Before coming to Altarum, Dr. Lynn was a consultant to the administrator of the Centers for Medicare & Medicaid Services, a faculty member of the Institute for Healthcare Improvement,

and a clinical expert in improvement for the Care Transitions Project at the Colorado Foundation for Medical Care. She has also been a senior researcher at RAND and a professor of medicine and community health at Dartmouth Medical School and George Washington University. Dr. Lynn has published more than 250 professional articles, and her dozen books include *MediCaring Communities*, a guide for reforms; *The Handbook for Mortals*, a guide for the public; *The Common Sense Guide to Improving Palliative Care*, an instruction manual for clinicians and managers seeking to improve quality; and *Sick to Death and Not Going to Take it Any More!*, an action guide for policy makers and advocates. She has also authored amicus briefs for key appellate court cases and has been often interviewed by reporters. Dr. Lynn is a member of the National Academy of Medicine and the National Academy of Social Insurance, a fellow of the American Geriatrics Society and The Hastings Center, and a master of the American College of Physicians. Her areas of expertise include chronic disease management, community health, managed care, end-of-life care, and the continuum of care.

**David Magnus, Ph.D.,** is the Thomas A. Raffin Professor of Medicine and Biomedical Ethics and a professor of pediatrics and medicine at Stanford University, where he is the director of the Stanford Center for Biomedical Ethics and co-chair of the Ethics Committee for the Stanford Hospital. He is the former president of the Association of Bioethics Program Directors and is the editor-in-chief of the *American Journal of Bioethics*. He has published articles on a wide range of topics in bioethics, including research ethics, genetics, stem cell research, organ transplantation, and end-of-life and patient communication. He was a member of the Secretary of Agriculture's Advisory Committee on Biotechnology in the 21st Century and currently serves on the California Human Stem Cell Research Advisory Committee. He is the principal editor of a collection of essays titled *Who Owns Life?* (2002) and his publications have appeared in the *New England Journal of Medicine*, *Science*, *Nature Biotechnology*, and the *British Medical Journal*. He has appeared on many radio and television shows, including *60 Minutes*, *Good Morning America*, *The Today Show*, *CBS This Morning*, *FOX News Sunday*, *ABC World News*, and NPR. In addition to his scholarly work, he has published opinion pieces in the *Philadelphia Inquirer*, the *Chicago Tribune*, the *San Jose Mercury News*, and the New Jersey *Star-Ledger*.

**Frances Norwood, Ph.D.,** is an assistant research professor in the Department of Anthropology and the Institute for European, Russian, and Eurasian Studies at George Washington University. She recently served as the president of the Washington Association of Professional Anthropologists. With a Ph.D. in medical anthropology from the University of California,

San Francisco, and the University of California, Berkeley, Dr. Norwood has more than 20 years of experience conducting health policy research on innovations in home- and community-based care, long-term care, and end-of-life supports for persons who are elderly and persons living with disabilities in the United States and the Netherlands. She is the author of a number of articles on chaplaincy and end-of-life care and is a recipient of the Margaret Mead Award for her book *The Maintenance of Life* (2009).

**Bregje Onwuteaka-Philipsen, Ph.D.,** is a professor of end-of-life research at Vrije Universiteit Medical Center in Amsterdam, the Netherlands. She leads the research line "public health at the end of life" at the department of public and occupational health. This is part of the research program Aging and Later Life of the Amsterdam Public Health Research Institute. The main themes of this research line are palliative care, advance care planning, and end-of-life decisions. Furthermore, she is the chair of the Vrije Universiteit Medical Center Expertise Center for Palliative Care, in which all care, educational, and research activities in the field of palliative care come together. She has ample experience in leading and participating in national and international research projects. She leads the Dutch nationwide monitoring of end-of-life decision making and euthanasia regulation, which has taken place every 5 years since 1990 (before and after the enactment of the euthanasia law in 2002). She has been involved since 1995 and has led it since 2005. In 2001 this study was combined with a European Community study (EC 5th Framework), making it possible to compare end-of-life decision making between countries for the first time. She has more than 250 publications listed in PubMed.

**David Orentlicher, M.D., J.D.,** is the Cobeaga Law Firm Professor at the University of Nevada, Las Vegas (UNLV), William S. Boyd School of Law and the co-director of the UNLV health law program. Nationally recognized for his expertise in health law and constitutional law, Dr. Orentlicher has testified before Congress, had his scholarship cited by the U.S. Supreme Court, and has served on many national, state, and local commissions. A graduate of Harvard Medical School and Harvard Law School, Dr. Orentlicher is the author of *Matters of Life and Death* and co-author of *Health Care Law and Ethics*, now in its 9th edition. He has published numerous articles and essays on a wide range of topics, including physician aid-in-dying, health care reform, reproductive decisions, affirmative action, and presidential power. Dr. Orentlicher's work has appeared in leading professional journals, such as the *New England Journal of Medicine* and the *Journal of the American Medical Association* (*JAMA*), as well as in *The New York Times*, *Time*, *USA Today*, *CNN Opinion*, the *Chicago Tribune*, and other major newspapers. Dr. Orentlicher also has taught as

an adjunct or visiting professor at the University of Chicago Law School, Northwestern University School of Medicine, and Princeton University. He is a member of the American Law Institute and a former president of the American Society of Law, Medicine & Ethics. Dr. Orentlicher previously directed the American Medical Association's Division of Medical Ethics, where he drafted the American Medical Association's first patient's bill of rights and many other guidelines relied upon by courts and government agencies, and he has practiced both law and medicine. Between 2002 and 2008, Dr. Orentlicher served in the Indiana House of Representatives, where he authored legislation to promote job creation, protect children from abuse and neglect, and make health care coverage more affordable.

**Steven Pantilat, M.D.,** is a professor of medicine in the Department of Medicine at the University of California, San Francisco (UCSF), the Kates-Burnard and Hellman Distinguished Professor in Palliative Care, and the founding director of the UCSF Palliative Care Program, which received a Circle of Life Award from the American Hospital Association in 2007. Dr. Pantilat is an internationally recognized expert in palliative care. He is a leading voice for changing the health care system and creating innovative programs to improve care for people living with serious illness. Dr. Pantilat is the director of the Palliative Care Quality Network, a national collaboration of 100 palliative care teams focused on improving the quality of care. He also directs the UCSF Palliative Care Leadership Center. Dr. Pantilat wrote a book titled *Life After the Diagnosis: Expert Advice on Living Well with Serious Illness for Patients and Their Caregivers* (DaCapo Lifelong Books, 2017). He has also published more than 100 peer-reviewed scientific papers, authored two dozen book chapters, and co-edited with colleagues at UCSF two textbooks on palliative care titled *Care at the Close of Life* and *Hospital-Based Palliative Medicine*. Dr. Pantilat is board certified in hospice and palliative medicine and in internal medicine with focused practice in hospital medicine. Dr. Pantilat was elected a master of hospital medicine by the Society of Hospital Medicine in 2014 and is a fellow of the American Academy of Hospice and Palliative Medicine. In 2007 he was a Fulbright Senior Scholar at the Royal Prince Alfred Hospital in Sydney, Australia. He served as the president of the Society of Hospital Medicine in 2005–2006 and is the former chair of the ethics committee for the Society of Hospital Medicine. Dr. Pantilat serves on the UCSF Medical Center ethics committee.

**Gary Pasternak, M.D., M.P.H.,** is the medical director at Mission Hospice and Home Care in San Mateo, California, and the co-director of the Mission House, a residential hospice home. He is board certified in

internal medicine and hospice and palliative medicine. Dr. Pasternak participated in developing Mission Hospice guidelines for implementing the California End of Life Option Act (EOLOA) and assists patients and families with the EOLOA.

**Richard Payne, M.D.,** is the John B. Francis Chair in Bioethics at the Center for Practical Bioethics in Kansas City, Missouri. As of July 1, 2017, he was the Esther Colliflower Professor of Medicine and Divinity (Emeritus) at Duke Divinity School at Duke University. Dr. Payne created the Initiative to Improve Palliative Care for African Americans (IIPCA) in 1999 as a 501(c)(3) organization to promote education and research to improve access to pain management and palliative and end-of-life care for African American patients. He also directed the creation a palliative care curriculum for clinicians to address the needs of African American patients (APPEAL), which has been taught widely throughout the country. Dr. Payne created and directed a community-based palliative care program, the Harlem Palliative Care Network, to address the needs of medically underserved patients and families in New York City. This program eventually created the first inpatient hospice unit for the Harlem community, located in North General Hospital. He is the former chief of pain and symptom management at the MD Anderson Cancer Center and the chief of pain and palliative care service at Memorial Sloan Kettering Cancer Center. Dr. Payne's work at Duke included directing the Institute for Care at the End of Life, which focused on connections between faith and medical communities to improve care of the serious and terminally ill. He also created several programs with Duke Divinity School and the Center for Practical Bioethics to educate pastors and lay faith leaders in African American churches in palliative care. Dr. Payne is board certified in neurology, pain medicine, and palliative care. He has more than 275 publications in these fields. He has also edited four books, given several endowed lectures, and received numerous awards in pain management, palliative care, and ethics.

**Cheryl Phillips, M.D., AGSF,** is the president and chief executive officer of the Special Needs Plans Alliance, a national leadership association for special needs and Medicare/Medicaid plans serving vulnerable adults. Prior to this she was the senior vice president for public policy and health services at LeadingAge. She has also served as the chief medical officer of On Lok Lifeways, the originator of the PACE (Program of All-Inclusive Care for the Elderly) model based in San Francisco, California, and the medical director for senior services and chronic disease management for the Sutter Health System, a network of doctors, hospitals, and other health providers in Northern California. As a fellowship-trained

geriatrician, her clinical practice focused on nursing homes and the long-term care continuum. While at Sutter Health, she developed and led a care coordination program for high-risk seniors enrolled in the Medicare Advantage plan. Dr. Phillips is a past president of the American Geriatrics Society and also a past president of the American Medical Directors Association, the physician organization for long-term care. She continues to serve on multiple technical advisory groups for chronic care, nursing home quality, and home- and community-based services and has provided multiple testimonies to the U.S. Congress. She served as a primary care health policy fellow under Secretary of Health and Human Services Tommy Thompson and she was appointed by the Governor of California as a California commissioner on aging and appointed to the Olmstead Advisory Committee for California. Dr. Phillips is on the board of directors of the SCAN Foundation.

**Thaddeus Pope, J.D., Ph.D.,** is the director of the Health Law Institute and a professor of law at the Mitchell Hamline School of Law in Saint Paul, Minnesota. He is also an adjunct professor with the Australian Centre for Health Law Research at Queensland University of Technology, an adjunct associate professor with the Alden March Bioethics Institute at Albany Medical College, and a visiting professor of medical jurisprudence at St. Georges University. Dr. Pope has published more than 130 publications in leading medical journals, law reviews, bar journals, nursing journals, bioethics journals, and book chapters. He co-authored the definitive treatise *The Right to Die: The Law of End-of-Life Decisionmaking* and he runs the Medical Futility Blog. Dr. Pope works to calibrate the balance between individual liberty and public health in the end-of-life medical treatment context. Specific research topics have included medical futility, unwanted medical treatment, ethics committees, brain death, advance directives, surrogate decision making, unrepresented patients, aid-in-dying, and voluntarily stopping eating and drinking. More recently, Dr. Pope has been innovating new legal tools to better ensure fair internal dispute resolution mechanisms and adequate informed consent with patient decision aids. Prior to joining academia, Dr. Pope practiced at Arnold & Porter, and clerked on the U.S. Court of Appeals for the Seventh Circuit. Dr. Pope earned a J.D. and a Ph.D. in philosophy and bioethics from Georgetown University.

**Timothy Quill, M.D.,** is the Thomas and Georgia Gosnell Distinguished Professor in Palliative Care at the University of Rochester Medical Center (URMC), where he is also a professor of medicine, psychiatry, medical humanities, and nursing. He was the founding director of the URMC Palliative Care Division and a past president of the American Academy

of Hospice and Palliative Medicine. Dr. Quill has published and lectured widely about various aspects of the doctor–patient relationship, with special focus on end-of-life decision making, including delivering bad news, non-abandonment, discussing palliative care earlier, and exploring last-resort options. He is the author of several books on end-of-life care and more than 150 articles published in major medical journals. Dr. Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the U.S. Supreme Court (*Vacco v. Quill*). Dr. Quill received his undergraduate degree from Amherst College and his M.D. from the University of Rochester. He completed his internal medicine residency and a fellowship in medicine/psychiatry liaison at the University of Rochester School of Medicine and Dentistry. Dr. Quill is a fellow in the American Academy of Hospice and Palliative Medicine, a master in the American College of Physicians, and an American Board of Medical Specialties–certified palliative care consultant.

**Peter Reagan, M.D.,** is a retired family physician who practiced for more than 30 years in Portland, Oregon. Dr. Reagan helped found a privately owned primary care clinic, Portland Family Practice, which provides full-spectrum care for all ages, including a large obstetrical component, inpatient pediatric and internal medicine, fairly extensive minor surgery, and frequent assisting in major surgery. When the Oregon Death with Dignity Act was on the ballot in 1994, Dr. Reagan, as a sympathetic physician, was involved in advocating for passage of the law. When the law went into effect 3 years later, he was asked to write the first legal prescription for aid-in-dying in the United States. During his time as a physician, Dr. Reagan wrote perhaps 25 prescriptions, of which perhaps 15 were used. After he retired from clinical practice in 2011, Dr. Reagan volunteered as a medical director for Compassion & Choices in Portland for 4 years, gaining experience in the practice of aid-in-dying as a consultant, both for individual cases and in the development of protocols and policies. Dr. Reagan has been asked to speak on many aspects of aid-in-dying at venues across the United States and Canada.

**Omega Silva, M.D.,** is a professor emeritus of medicine at George Washington University, and she was a medical review officer for Employee Health Programs in Bethesda, Maryland. In 1999 Dr. Silva was appointed president-elect of the American Medical Women's Association. Dr. Silva graduated cum laude with honors in chemistry from Howard University in 1958. She spent the next 5 years working as a chemist at the National Institutes of Health, and in 1963 she returned to Howard University to train as a physician. After earning an M.D. in 1967, Dr. Silva completed

a residency in internal medicine at the Veterans Administration Hospital in Washington, DC, and from 1970 to 1974 served as a fellow in endocrinology at George Washington University. In 1975 she was appointed an assistant professor of medicine at George Washington University, and in 1977 she was appointed an associate professor of oncology at Howard University. Dr. Silva has held academic posts at both institutions ever since, becoming a full professor at Howard in 1985 and at George Washington in 1991. From 1977 to 1996 Dr. Silva was the assistant chief of the metabolic section and the chief of the diabetic clinic at the Veterans Affairs Medical Center in Washington, DC. Dr. Silva served as the president of the American Medical Women's Association from 2000 to 2002. She has served on six separate advisory groups for the National Institutes of Health and was a consultant to the Food and Drug Administration's immunology section from 1981 to 1989. Dr. Silva has also served on the board of directors for the Howard University Medical Alumni Association, the National Association of Veterans Affairs Physicians, the American Medical Women's Association, and the Foundation for the History of Women in Medicine. In 1984 Dr. Silva received a letter of commendation from the President Reagan, and in 1995 she was given a letter of thanks from President Clinton for her participation in health care reform. In 2003 Dr. Silva was elected to a mastership at the American College of Physicians. She is also listed in *American Men and Women of Science*, *Who's Who in Black America*, *Who's Who in Professional and Executive Women*, and *Who's Who of American Women*.

**Anita Silvers, Ph.D.,** is a professor and the former chair of the Philosophy Department at San Francisco State University (SFSU) and an affiliate of the SFSU Health Equity Institute. Disabled by polio as a child, Dr. Silvers is a leading advocate for equality for persons with disabilities. Her papers and books have contributed to the legal interpretation of the Americans with Disabilities Act, enacted in 1990. Her groundbreaking and acclaimed monograph *Disability. Difference. Discrimination: Formal Justice* (1998) is widely cited in legal affairs. *Americans with Disabilities* (2000), which she co-edited with Leslie Pickering Francis, anthologizes essays by leading philosophers as well as legal theorists, bioethicists, and policy makers on the foundational concepts of disability law and policy. On the faculty at SFSU since 1967, Dr. Silvers has worked to make access and disability services available on California college campuses. In 1980 she was appointed by President Jimmy Carter to serve on the National Council for the Humanities, the governing board of the National Endowment for the Humanities. Dr. Silvers has received the Phi Beta Kappa Society's Lebowitz Prize for philosophical achievement and contribution, the Quinn Prize for service to philosophy and philosophers from

the American Philosophical Association, the California State University System's Wang Outstanding Faculty Excellence Award, and the inaugural Human Rights Award from the California Faculty Association. Dr. Silvers is regarded as an authority on social philosophy, medical ethics, and bioethics.

**Helene Starks, Ph.D., M.P.H.,** is an associate professor in the Department of Bioethics and Humanities, School of Medicine, and adjunct associate professor in the Departments of Health Services, Family Medicine, and Pediatrics at the University of Washington (UW). She is also the director of the Metrics, Quality & Evaluation Core for the Cambia Palliative Care Center of Excellence and core faculty in the Graduate Certificate in Palliative Care, offered jointly by the schools of nursing and medicine. She received an M.P.H. in health policy and administration from the University of California, Berkeley, and a B.A. in communications and a Ph.D. in health services research from UW. Dr. Starks's current research interests include issues related to palliative and end-of-life care for patients, their family members, clinicians, and health systems; medical decision making and clinician–patient communication; qualitative and mixed-methods research; stakeholder engagement; implementation and dissemination science; and quality improvement and systems change. She is currently leading a study on patient and family experiences with the California End of Life Option Act. As the director of the Metrics, Quality & Evaluation Core for the Cambia Palliative Care Center of Excellence, she led the development and implementation of a metrics reporting system to support all four UW Medicine hospitals in achieving certification in specialty palliative care from the Joint Commission in spring 2016. Dr. Starks is also part of a team developing ongoing quality metrics using electronic health records data for 18 measures of quality primary and specialty palliative care. She currently serves on the Quality Committee for the American Academy of Hospice and Palliative Medicine to promote further dissemination of these quality metrics.

**Thomas Strouse, M.D.,** is a professor of clinical psychiatry and the inaugural holder of the Maddie Katz Chair in Palliative Care Research and Education. He is also the medical director of Stewart and Lynda Resnick Neuropsychiatric Hospital at the University of California, Los Angeles (UCLA), and the vice-chair for clinical affairs in the David Geffen UCLA School of Medicine Department of Psychiatry. Dr. Strouse has been a faculty member at UCLA since he completed his residency training there in 1991. Early in his career he was director of the UCLA Consultation/Liaison Psychiatry Service and worked closely with the UCLA liver trans-

plant program for more than a decade. He served from 1994 to 2007 as the director of cancer pain management and supportive oncology services at the Outpatient Cancer Center at Cedars-Sinai Medical Center. Along with his current efforts to promote palliative care clinical research within the UCLA Health System, Dr. Strouse continues to attend on the Ronald Reagan UCLA Medical Center Palliative Care Consultation Service and is actively engaged with UCLA's Operation Mend, a program for wounded U.S. servicemen and women. In 2003 he received the Robert T. Angarola Award, the highest honor bestowed by the Southern California Cancer Pain Initiative to the individual most allied with improving quality of life for persons with cancer in a given year. Dr. Strouse is a fellow of the Academy of Psychosomatic Medicine and an American Psychiatric Association distinguished fellow and a member of the American College of Psychiatrists. He is board certified in general psychiatry, psychosomatic medicine, and hospice/palliative medicine. In July 2014 Dr. Strouse assumed the role of chair of the American Board of Internal Medicine Test Committee responsible for writing the certifying exam for all North American physician candidates for the American Board of Medical Specialties subspecialty of hospice and palliative medicine. In 2010 he was appointed associate editor of the *Journal of Supportive Oncology* and is now the editor of the *Journal of Community and Supportive Oncology*; in 2017 he became an associate editor of the *Journal of Palliative Medicine*.

**Daniel Sulmasy, M.D., Ph.D.,** is the André Hellegers Professor of Biomedical Ethics in the Departments of Medicine and Philosophy at Georgetown University, where he is a faculty member of the Pellegrino Center for Clinical Bioethics and a senior research scholar in the Kennedy Institute of Ethics. He has served on numerous governmental advisory bodies, including the Presidential Commission for the Study of Bioethical Issues from 2010 to 2017.

**James A. Tulsky, M.D.,** of the Dana-Farber Cancer Institute has a longstanding interest in doctor–patient communication and quality of life in serious illness, and he has published widely in these areas. His current research focuses on the evaluation and enhancement of communication between oncologists and patients with advanced cancer; the identification of clinical, psychosocial, and spiritual trajectories of patients at the end of life; development of self-management interventions for patients with life-limiting illness; and evaluating the role of palliative care in congestive heart failure. He is a founding director of VitalTalk (www.vitaltalk.org), a nonprofit devoted to nurturing healthier connections between clinicians and patients through communication skills teaching.

**Neil Wenger, M.D., M.P.H.,** is a professor of general internal medicine and health services research at the University of California, Los Angeles (UCLA). He directs the UCLA Health Ethics Center and is a general internist who specializes in the care of the complex patient. He is a consulting researcher at RAND.

**Matthew Wynia, M.D., M.P.H.,** is the director of the Center for Bioethics and Humanities at the University of Colorado. Trained in internal medicine, infectious diseases, public health, and health services research, Dr. Wynia currently splits his time between clinical, administrative, research, and outreach responsibilities at the American Medical Association (AMA) and the University of Chicago, both in Chicago, and the University of Colorado's Anschutz Medical Campus. In July 2015 he moved to Colorado to serve as the full-time director of the university's Center for Bioethics and Humanities. Dr. Wynia has developed a research institute and training programs focusing on bioethics, professionalism, and policy issues (the AMA Institute for Ethics) and founded the AMA's Center for Patient Safety. He has led projects on a wide variety of issues related to ethics and professionalism, including understanding and measuring the ethical climate of health care organizations and systems; ethics and quality improvement; communication, team-based care, and engaging patients as members of the team; defining physician professionalism; public health and disaster ethics; medicine and the Holocaust; and inequities in health and health care. He has delivered more than two dozen named lectures and visiting professorships nationally and internationally and is the author of more than 140 published articles, chapters, and essays; the co-editor of several books; and the co-author of a book on fairness in health care benefit design. He is a past president of the American Society for Bioethics and Humanities, and a past chair of the ethics forum of the American Public Health Association and the ethics committee of the Society for General Internal Medicine.